FasterCures
The Center for Accelerating Medical Solutions

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Think Research

Using Electronic Medical Records to Bridge Patient Care and Research

About This Report

FasterCures believes that the study of large samples of medical records or clinical datasets could be an essential step toward understanding the etiology and progression of disease, treatment methods, and outcomes across varied populations and disease groups.

To better understand the landscape of electronic medical record (EMR) system adoption and evaluate the challenges and opportunities involved in developing research uses of this vast resource, FasterCures commissioned this study to:

1) conduct a broad overview and characterization of current efforts to promote EMRs and their potential research use, and
2) assess what is needed to optimize the creation and use of such databases for research purposes.

*This analysis rests on the premise that **as the healthcare system addresses the challenges of widespread adoption of electronic patient record systems, research capacity should be a part of the architecture**.*

The intended audiences for this report are members of the clinical care and research communities and policymakers. The project focus was restricted to assessing existing and potential aggregations of medical record/clinical information (in most cases electronically stored), not tissue banks or other repositories of human biological material, and not databases of basic research information (even when human-related).

Project staff scanned the environment to better understand the many possible configurations of clinically related information, including:

- *databases of complete medical records;*
- *databases created primarily for medical research;*
- *disease-specific databases;*
- *specialized databases;*
- *proprietary entities; and*
- *hospital-based systems.*

Project staff reviewed the general characteristics of each broad category of database—for example, the type and quality of data (including any information about nomenclature/terminology used), the language/software used (including any relational database system used), current research accessibility, and the purpose of the collection. In addition, they conducted literature reviews, searched information available through the Internet, and contacted several key professional, governmental, and patient-based groups to assess the depth and breadth of this universe. Extensive interviews were conducted with representatives of healthcare and research institutions that have deployed EMR systems and clinical researchers who are users or potential users of EMR systems.

This report focuses on the implementation challenges faced by healthcare systems and providers in moving to EMR systems, addresses the potential for using EMRs in research, provides examples of EMR systems, including descriptions of model efforts by some healthcare systems to create research-friendly EMR systems, and offers strategies for moving forward. In addition, the project has yielded an extensive resource guide listing many of the public and private organizations and collaborations involved in advancing the use of EMRs in health and in research, relevant publications and news sources, sources for information related to the selection of EMR systems, and a variety of other resources related to EMRs and electronic health information.

Acknowledgments

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As the healthcare system addresses the challenges of widespread adoption of electronic patient records, research capacity should be part of the architecture.

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I. Introduction: Connecting the Bench to the Bedside

The frontier of medical science has rarely been as exciting and as full of opportunity as it is today. From basic science through clinical research to health services research, the opportunities made available through the impressive advances of recent decades in the biomedical, physical, computational, and behavioral and social sciences have brought us to a place of unprecedented opportunity.

It is not just that there is more to do, there is everything to do. Biological science, with medicine bobbing somewhere in its wake, is under way, but only just under way. ***Biologist Lewis Thomas***

Successful completion of the Human Genome Project has launched scientists into the new world of genomics and proteomics, a journey that will lead to the eventual understanding of every human protein and its role in both health and disease. The next challenge will be to identify the functions of the genes that have been mapped, the proteins for which they code, and the functions of those proteins in the body.

To understand the relationships between this molecular information and human health, population-based and clinical studies are needed, requiring the generation, storage, and analysis of enormous quantities of epidemiologic, genotypic, and phenotypic data. To understand the connections between genes, proteins, and the environment, sophisticated comparisons must be conducted, and these comparisons cannot be done by hand or by eye or patient by patient. It is the collective observations of hundreds, even thousands, of patients that will shine a light on these associations.

Using properly designed databases and powerful computers, informatics can provide a view of the relationships between health and illness and unwrap the mysteries of human variation.

You can observe a lot just by watching.
Yogi Berra

Now that the genome is mapped, scientists will have to rely on clinical investigation to conduct gene-based studies, to redefine the biology and the phenotypes of disease, and to refine diagnostic classifications. Clinical data and observations will be crucial in the effort to connect the dots between molecular discoveries and human health and disease.

It is critical that we build a solid connection between the bench and the bedside.

Computers can display patterns that rarely would be found if searched for with traditional approaches and techniques. The creation and development of databases and database technologies—that is, methods for storing, retrieving, sharing, and analyzing clinical and biomedical data—is the next essential step in the Human Genome Project.

Clinical observations have been fundamental to some of the more important breakthroughs in medicine over the past 50 years. For example, in the 1980s, clinical researchers Robin Warren and Barry Marshall observed that many of their patients with inflammation of the stomach (gastritis) also tested positive for the presence of a bacterium. After looking at 100 patients they discovered that this bacterium also was present in every patient who suffered from a duodenal ulcer. They eventually isolated the bacterium, *Helicobacter pylori*, and demonstrated that antimicrobial therapy would

eliminate *H. pylori* from the stomach. Thus, for the first time, gastric ulcers could be cured completely. Such discoveries have had a profound effect on both the management of gastroduodenal disease and the clinical practice of gastroenterology.[1]

Warren and Marshall's work, as well as that of numerous other clinical investigators over the past 50 years, demonstrates that clinical observations made on a case-by-case basis can be critical, but are difficult to assess in the absence of aggregate data. As such, databases and biological repositories have become ever more essential resources for clinical scientists.

New Opportunities for Clinical Research

Clinical investigators are faced with more opportunity and data and a greater need to organize the data in a meaningful and coherent manner than ever before. Having large amounts of computational expertise has become a necessity. Clinical data gathered in the course of routine medical care—if systematically collected, routinely stored, and widely accessible—could provide researchers with the clues needed to unravel many medical mysteries.

No longer does clinical research require that an investigator and patient be in the same room. The electronic storage and transmittal of clinical data and information associated with stored human biological materials is transforming clinical research. As more information from clinical trials and clinical research becomes available, the need for standardization and interoperability of clinical databases will increase. A system of interoperable databases would allow clinical researchers to track more efficiently any finding back to its basic scientific roots.

In addition to the need to analyze the associations between clinical observations and genomic and proteomic discoveries, systematic clinical observation is the foundation for evidence-based medicine, which takes the best available information from clinical trials and observational studies and applies it in clinical practice. Only by documenting what happens in the clinical setting—observing the experiences of many patients—can we fully understand and address the difficulties of translating the unambiguous results of clinical trials into the ambiguous world of clinical practice.

The complexity of issues that affect human health—from the genomic and proteomic levels to the culture and locale of the institutions that provide healthcare services—requires that there be a more comprehensive and collaborative approach to connecting the worlds of science and the clinic. Clinical and health services researchers have been working toward this goal for decades. In recent years, new tools in the form of information technology have arrived to help them.

The Value of Medical Records to Clinical Research

There is a longstanding research practice of combing medical records to glean information that could provide clues about the onset and progression of disease and to improve disease management and outcomes (see Box A). In the past, paper medical records studies have been used to:

- monitor the health of the population and detect emerging health problems;
- identify populations at high risk for disease;
- determine the effectiveness of treatment(s);
- assess and quantify prognoses;
- assess the usefulness of diagnostic tests and screening programs;
- influence policy through cost-effectiveness analysis;
- support administrative functions; and
- monitor the adequacy of care.[2]

The potential value of medical records data to clinical research could be magnified by the computing power associated with a system of digitized, or electronic, medical records.

In theory, any information that can be placed in a paper record can be placed in an electronic record. However, many institutions migrating toward an EMR system are struggling with the challenge of converting unstructured text, data, and images into a standard format. Many different types of patient data can be included in an EMR:

- medical history;
- physical examination;
- diagnoses;
- clinical activities;
- diagnostic tests;
- therapeutic (drugs, devices, procedures, rehabilitation programs); and
- administrative data (claims, billing, outcomes).

Widespread adoption of EMR systems is an important step toward delivering on the promise of longer lives and better health in this century. In the past decade there has been increasing movement in the United States toward storage of patient health information in EMRs and more recently toward personal health records (PHRs). EMR is a generic term used to describe computer-based patient medical records (see Box B). For the most part, the development of EMRs is being promoted as a necessary step to improve care.

BOX A What Is a Medical Record?

A medical record is a confidential record that is kept for each patient by a healthcare professional or organization. It contains the patient's personal details (such as name, address, date of birth), a summary of the patient's medical history, and documentation of each event, including symptoms, diagnosis, treatment, and outcome. Relevant documents and correspondence are also included. Traditionally, each healthcare provider involved in a patient's care has kept an independent record, usually paper-based. The main purpose of the medical record is to provide a summary of a person's contact with a healthcare provider and the treatment provided in order to ensure appropriate healthcare. Information from medical records also provides the essential data for monitoring patient care, conducting clinical audits, and assessing patterns of care and service delivery.

Terminology Used in This Report

Many terms are used to describe the patient electronic health or medical record (EHR or EMR), along with a multitude of often confusing acronyms. For the purposes of this report, the term EMR is used in two ways.

First, an EMR is the provider-created and provider-driven record used for patient care. The system encompassing these records generally consists of health records stored electronically in-house by the provider and under the provider's control. This system may have full interoperability within a particular healthcare enterprise (hospital, clinic, practice) and at this time can interact with a few other systems—primarily administrative, claims, and some diagnostic systems, such as laboratories—that are outside the enterprise.

A second common use of the term EMR refers to the ideal system that many envision and are working to develop. For example, the National Health Information Network (NHIN) is an effort by the federal government to ensure widespread deployment of health information technology in the United States throughout the public and private sectors. Its goal is a comprehensive knowledge-based network of interoperable systems of clinical, public health, and personal health information that would improve medical care and decision-making by allowing healthcare providers access to up-to-date electronic health records for patients who have authorized it, whenever and wherever the patient receives care.[3]

We chose to use EMR versus EHR because we are describing the databases of today. Generally, EHR refers to the combination of the medical record created by the medical care system and personal health information. In our scan of the literature, the use of both terms is decidedly mixed. When EHR is used, it tends to be mentioned as a term for the future. In addition, EMR often refers to a systemic approach to keeping medical records.

The ideal EMR system for patient care would consist of complete and accurate electronic patient healthcare records stored in systems that would be interoperable with the systems of most or all other healthcare institutions and entities that are involved in patient care.

1 Marshall BJ, Warren JR, "Unidentified Curved Bacilli in the Stomach of Patients with Gastritis and Peptic Ulceration," *Lancet*, 1984;1:1311-1315.
2 Melton LJ, 3rd, "The Threat to Medical-Records Research," *N Engl J Med*, 1997;337(20):1466-1470.

3 See aspe.hhs.gov/sp/NHII/FAQ.html.

BOX B *Terminology Used to Describe Electronically Stored Patient Information*

CMR (common medical record) *Has been used to refer to the various pieces of information about a patient that are expected to be available as a minimal set of data. Sometimes CMR stands for computerized medical record—that is, any document imaging-based electronic patient record system.*

CPR (computer-based patient record) *Originated with the Institute of Medicine in its 1991 report, "Computer-Based Patient Records: An Essential Technology for Health Care," to refer to a structured, digitized, and fully accessible health record. It also has been used to refer to a lifetime patient record that includes all information from all specialties (including dental and psychiatric care). This term often is used interchangeably with EMR.*

EHR (electronic health record) *Often used as a generic term for all electronic patient care systems.*

EMRS (electronic medical record systems) *Often used synonymously with EMR to refer to EMR systems.*

EPR (electronic patient record) *Similar to the CPR, but does not necessarily contain a lifetime record and would not include dental, behavioral, or alternative care information. It focuses on information gathered by a provider and relevant only to services provided by that provider.*

ICRS (integrated care record services) *Term used in the United Kingdom for EMR.*

PCR (patient-carried record) *All the information about a patient is carried on a token or card by the patient.*

PHR (patient health record) *Managed and controlled by the patient and is mostly Web-based.*

PMRI (patient medical record information) *Language used by the Department of Health and Human Services/National Committee on Vital and Health Statistics.*

VPR (virtual patient record) *Records that are electronically created, edited, and stored in electronic digitized media. This also can refer to viewing data that might be configured differently at different locations, while mapped into a common format at the time the record is accessed.*

Benefits: EMRs Can Improve Health

The recognition of the vast benefits EMR systems will provide in the healthcare delivery enterprise continues to grow. Benefits are expected to include:

- fewer medical errors, which are estimated to be responsible for as many as 44,000 to 98,000 deaths a year;[4]
- the provision of more efficient healthcare services;
- reduced utilization;
- improved ability to manage chronic disease;
- improved health status;
- streamlined work processes; and
- more accurate and complete medical records.[5]

In addition, it has been estimated that moving to electronic records could cut 10 percent or more from the nation's $1.7 trillion each year in healthcare spending by reducing paper handling and eliminating unnecessary or duplicative tests—an enormous cost savings.[6] A completely standardized and interoperable national healthcare information exchange could save the U.S. healthcare system $77.8 billion a year if fully implemented. This is three times the savings of a national network built without standardization.[7,8]

In theory, storing patient data electronically in an EMR provides several advantages over paper copies.

4 See the Institute of Medicine report, *To Err Is Human: Building a Safer Health System*, 1999, www.nap.edu/openbook.php?record_id=9728&page=1#pagetop.

5 A recent study has shown that clinical health information was missing from patient files in 13.6 percent of primary care visits. See article in *JAMA*, Smith PC et al., "Missing Clinical Information During Primary Care Visits," 2005;293:565-571, jama.ama-assn.org/cgi/content/abstract/293/5/565.

6 Brewin B, "HHS Pushes Electronic Health Records," *ComputerWorld*, July 21, 2004, www.computerworld.com/governmenttopics/government/policy/story/0,10801,94665,00.html. Brewin also reports at www.fcw.com/article84332-10-15-04-Web, October 15, 2004, that, "It will take an investment of $500 billion to $700 billion in healthcare information technology systems during the next decade to meet President Bush's goal of using technology to wring some 20 percent out of the nation's annual $1.7 trillion healthcare bill. That's the view of top executives of healthcare IT vendors and hospital chief information officers, who said the $500 billion figure represents a 3 percent investment of total industry revenues into IT and the $700 billion figure represents a 4 percent investment. Both figures are lower than in industries such as finance and manufacturing, which plow between 5 percent and 7 percent of their revenues into IT."

7 Versel N, "CITL Study Suggests Complete Electronic Standardization Could Save $77 Billion," *Health-IT World ENews*, February 1, 2005, www.health-itworld.com/enews/02-01-2005_515.html; Walker J et al., "The Value of Health Care Information Exchange and Interoperability," *Health Aff*, January 19, 2005, content.healthaffairs.org/cgi/content/full/hlthaff.w5.10/DC1.

8 See examples of reported cost savings or other benefits that have resulted from information technology initiatives across the United States in General Accounting Office, *Information Technology: Benefits Realized for Selected Health Care Functions*, GAO-04-224, October 2003, www.gao.gov/new.items/d04224.pdf.

First, electronic files can be readily accessed from anywhere, local or remote, across a communications link or network. Data that are stored in electronic formats can be retrieved electronically. Millions of records can be sifted through in seconds if the database has been appropriately designed and indexed. More than one user at a time can have access to them, and all service providers can share the same records.

Second, records created by multiple providers in different locations and units can be linked and shared to create a single record for the individual. The problem of record fragmentation can be resolved, and patient care can be shared among providers. Furthermore, all the graphic data (e.g., images), incoming letters (e.g., referrals), and auditory data (e.g., heart sounds, spoken notes) relating to a patient can be linked to his or her electronic record file using multimedia techniques.

Third, well-designed, computerized records can display different data views—for example, all current medications or problems; the last 10 full blood counts in graphic display; or test results for a specified admission or date range. The data in the record are no longer static and accessible only in the order and format determined by the writer, but can be dynamically displayed in any way that suits the needs of the viewer.

Fourth, the reporting functions for electronic records are streamlined. For example, patients' treatments can be assigned billing codes, statistical reports can be sent to public health agencies for surveillance purposes, and notifications (e.g., births and deaths) can be sent to public records offices. Automatic audit reports can be prepared, such as those focused on caseloads, services provided, lengths of stay, and costs of care.

II. EMR Systems: A Critical Research Resource

In addition to the improvements that can be gained in patient care, EMR systems have the potential to provide clinical data essential to research. The application of information technology to patient records offers the promise of new knowledge obtained through integrating and analyzing data extracted from patients' clinical information, medical images, the environment, genetic profiles, and molecular and genomic research efforts (see Box C).

BOX C What Is the Universe of Patient Encounters?

The potential to gather data on thousands—even millions—of patient encounters provides an unprecedented opportunity to make the connection between science and health.

- *During 2002, an estimated 890 million visits were made to physician offices in the United States, an overall rate of 314.4 visits per 100 persons.*[9]
- *An estimated 33.7 million inpatients were discharged from nonfederal short-stay hospitals in 2002.*[10]

EMR databases should not be confused with research databases that are created specifically to answer a scientific question or set of questions (see Box D for examples). These databases, in general, contain very rich but very narrow information on subjects involved in the research. Only rarely, such as in longitudinal studies, do these databases contain complete information on individuals. Because they are created to answer a research question, they contain highly detailed data around a limited set of parameters that are likely to answer a research question.

Often a large database exists to monitor public health and conduct research—for example, infectious disease databases, birth defects and cancer registries, so-called vigilance databases available for post-marketing drug or medical device surveillance, and environmental exposure databases.

How Can EMRs Serve Research?

EMR systems could be used by researchers to form hypotheses, look for patterns, and perhaps most importantly, identify potential study participants who match the inclusion and exclusion criteria of a planned research study. Clinical researchers also foresee great potential for conducting post-marketing surveillance studies of new drugs to identify adverse events or improve prescribing and labeling practices.

Clinical trials are costly and time-consuming. Clinical research is constrained today by a clumsy method of acquiring the data needed for clinical trials, generally relying on manual capture of information onto data sheets that are then transcribed into computer databases for statistical analysis. This method is labor intensive, fraught with opportunities for error, and increasingly difficult to defend in light of the high costs associated with randomized clinical trials.

Daniel Federman, former Dean of Medical Education at Harvard Medical School, says that using EMRs to aid recruitment could reduce the cost of clinical research. "If we can drive cost down and save time, we can study more issues."

Much of the patient information collected for clinical trials already exists in the patient record. If clinical researchers could quickly import such information from the existing practice record into the research record, both time and money could be saved.[11]

EMR systems could speed data acquisition and searching, allow mass computing and sampling, and provide the research community access to a broader and more diverse patient population.

As physicians record new actions, outcomes, and demographics in EMRs, researchers will have access to more in-depth and clean data. For example, it often takes years to get a single data snapshot of a small patient population relative to a given condition.

9 Woodwell DA, Cherry DK, "National Ambulatory Medical Care Survey: 2002 Summary," *Adv Data*, 2004;(346):1-44.
10 Kozak LJ, Owings MF, Hall MJ, "National Hospital Discharge Survey: 2002 Annual Summary with Detailed Diagnosis and Procedure Data," *Vital Health Stat, Series 13*, 2005;(158):1-199.
11 Shortliffe EH, "The Evolution of Electronic Medical Records," *Acad Med*, 1999;74(4):414-419.

BOX D Sample Research and Surveillance Databases

ARAMIS (the Arthritis, Rheumatism, and Aging Medical Information System)[12]
A national chronic disease databank system that consists of parallel, longitudinal, clinical datasets from 11 diverse United States and Canadian locations. Data describe the courses of thousands of patients with rheumatic diseases and healthy community residents followed for more than 25 years. Unlike clinical studies based on medical records, ARAMIS data are collected with a prospective protocol using standard, defined data collection instruments.

Physicians Health Study[13]
A large, long-term, randomized cohort study initiated in 1982 to look at the effects of aspirin and beta-carotene on cancer and cardiovascular disease.

Surveillance, Epidemiology, and End Results Program (SEER)[14]
SEER, funded by the National Cancer Institute, maintains computerized data on cancer incidence, mortality, and survival for approximately 14 percent of the U.S. population in several defined geographic areas. Information is gathered from hospital medical records and pathology reports of cancer cases.

Vaccine Safety Datalink (VSD)[15]
Developed in 1990 by the Centers for Disease Control and Prevention in partnership with seven large health maintenance organizations to continually monitor vaccine safety, VSD is an example of a large-linked database (LLDB) and includes information on more than six million people. All vaccines administered within the study population are recorded. Available data include vaccine type, date of vaccination, concurrent vaccinations (those given during the same visit), the manufacturer, lot number, and injection site. Medical records are then monitored for potential adverse events resulting from immunization. The VSD project allows for planned vaccine safety studies as well as timely investigations of hypotheses. Uses of the database include examining potential associations between vaccines and a number of serious conditions and testing new vaccine safety hypotheses that result from the medical literature.

The research process that relies on paper medical records locked in unconnected file baskets is amazingly cumbersome, and the populations studied by most medical researchers are often small. With an EMR system, one could look at entire populations and know the impact of a new drug or device on, for example, diabetics, asthmatics, African American women over 65, or whatever population subset is chosen. Impact could be ascertained on a weekly, monthly, or yearly basis.

A recent study conducted with Kaiser Permanente records of the effects of COX-2 selective agents on heart disease demonstrates the power of this type of research access (see Box E). Following this and other studies, manufacturers of COX-2 selective agents voluntarily withdrew their products from the market pending further safety studies.

In another example, in 2000, researchers at four institutions in two states evaluated the use of a computer program to identify adverse drug events in the ambulatory setting.[16] Only institutions using an EMR system could participate in the study. The researchers collected information on all patient visits to primary care practices for a year. They used computer search methods for identifying adverse drug events, including diagnostic codes, allergy rules, computer event monitoring rules, and text searching, and concluded that computerized search programs of EMRs can detect adverse drug events.

To date, the focus of most efforts has not been on research, but rather to implement EMR systems to improve healthcare delivery and specifically on connecting provider communities for particular patient populations. For example, the Veterans Health Administration (VHA) health system has used its EMR system to improve the quality of care for veterans with schizophrenia[17] and veterans with chronic heart failure.[18]

The real long-term savings of EMR systems—both in terms of reducing healthcare costs and, more importantly, eliminating human suffering—will come from research that leads to earlier and better diagnosis, more effective cures, and methods for limiting the damage of disease.

12 See aramis.stanford.edu.
13 See phs.bwh.harvard.edu/index.html.
14 See www-seer.ims.nci.nih.gov.
15 See www.cdc.gov/nip/vacsafe/#VSD.
16 Honigman B et al., "Using Computerized Data to Identify Adverse Drug Events in Outpatients," *J Am Med Inform Assoc*, 2001;8(3):254-266.
17 Owen RR, Thrush CR, Cannon D, Sloan KL, Curran G, Hudson T, Austen M, Ritchie M, "Use of Electronic Medical Record Data for Quality Improvement in Schizophrenia Treatment," *J Am Med Inform Assoc*, 2004;11(5):351-357.
18 See wwwcf.nlm.nih.gov/hsr_project/view_hsrproj_record.cfm?PROGRAM_CAME=search_fields.cfm&NLMUNIQUE_ID=20024216&SEARCH_FOR=vista.

BOXE **Use of EMRs for Post-Marketing Research**

Investigators wanted to determine if celecoxib, ibuprofen, naproxen, rofecoxib, or other nonsteroidal anti-inflammatory drug (NSAID) use increases the risk of heart attack and death and whether the risk is similar among COX-2 selective agents. The six million Kaiser Permanente members in California were the focus of this study.

Computerized eligibility, hospitalization, outpatient visit, laboratory results, procedure, and outpatient drug prescription files are maintained for all members. All patients aged 18 to 84 treated with a COX-2 selective or nonselective NSAID between January 1, 1999, and December 31, 2001, were entered into the study cohort, beginning with their first prescription, and were followed until the end of the study period, disenrollment, heart attack, or death.

Once the study was completed, it was calculated that 1,394,764 patients contributed 2,295,168 person-years of observation time to the study, a feat that could not be imagined without access to computerized records.[19]

Research Uses of EMRs Should Not Be an Afterthought

With the potential benefits that EMR systems can offer, research cannot be an afterthought. Although medical and professional groups, such as the Physicians Electronic Health Record Coalition, the Association of American Medical Colleges, and the American Medical Association, are actively involved in efforts to foster EMR adoption to improve care, the research component is secondary to patient care.

The value of EMR systems in research already is being established, albeit slowly and incrementally. Numerous academic medical centers are in the early stages of EMR adoption generally, and many are contemplating the value of this as a research resource.

Even at single institutions, it is commonly the case that researchers are not consulted during the adoption and implementation of EMR systems. Henry Lowe, Chief Information Officer at Stanford University School of Medicine, considers this a missed opportunity.

"Research capabilities should be designed in at the onset of EMR implementation," said Lowe. "If we want to improve outcomes and develop an evidence-based model of healthcare, we have to eliminate the dichotomy between patient care and research. EMR systems provide a tremendous opportunity to bridge that gap."

At Stanford, Lowe is spearheading efforts to shape consistent, reliable clinical systems from the outset that will ultimately provide better data for research.

However, as valuable as EMRs could be to research, they could never duplicate the standardized, controlled data collection of clinical trials. Moreover, some areas of research just do not lend themselves to records research. For example, behavioral studies that are so important to disease prevention rely on assessing patient values and preferences, levels of exercise and diet, symptoms, and socioeconomic and cultural issues—all variables unlikely to be documented reliably in a patient record.

Perhaps the greatest and most pressing challenges to using the EMR for research is the slow rate of its adoption, as discussed in Section IV of this report. However, even where EMR systems are in place, their adaptability to research use faces significant challenges, such as the reliability of entered data, interoperability and access issues, vocabulary differences, proprietary interests, and privacy concerns (see discussion in Section V of this report).

These are challenges that can be met, given the will and the resources. The path to an EMR system that also serves the needs of researchers is a long one, but it is one that must be mapped, lest there be a missed opportunity. The promise that information technology offers must be harnessed to maximize today's opportunities.

19 Graham D et al., "Risk of Acute Cardiac Events Amongst Patients Treated with Cyclooxygenase-2 Selective and Non-selective Nonsteroidal Antiinflammatory Drugs," Conference on Pharmacoepidemiology, Bordeaux: International Society for Pharmacoepidemiology; 2004.

III. Pioneers, Innovators, and Inventors

A pessimist sees the difficulty in every opportunity; an optimist sees the opportunity in every difficulty. **Winston Churchill**

While there is a long way to go before EMRs can be widely used in research, clinical investigators are enthusiastic about the prospect. And many researchers have cited other applications of information technology already in development—for example, patient data warehouses, electronic data capture for investigator-initiated studies, and use of software systems for Institutional Review Board (IRB) review, grant submission, research monitoring and tracking, and basic data management and storage.

Although most healthcare practitioners and institutions in the United States are not yet ready to implement clinical information systems, a few have positioned themselves as pioneers in their use of EMR systems for research purposes. Not willing to wait for the idealized NHIN—a network of networks—several institutions have forged ahead to find ways to meld clinical practice data with research goals.

In this section we describe some of these efforts, which range from attempts to link EMRs across institutions or with existing clinical and research databases, to the development of combined patient care/research activities, databases of databases, and data warehouses. The top research priority for the greatest number of respondents to a survey by the Academic Health Center's Clinical Research Forum is the development of a research clinical repository or data warehouse. Thus, we include some examples of warehouses that are drawing interest.

The list is by no means comprehensive, but rather presents examples of promising approaches. We are confident that the list of institutions actively engaged in using EMR systems for research (other than traditional outcomes and health services research) is short.

Primary Focus: Clinical Care in Private Settings

Mayo Clinic: Rochester, Minnesota

Mayo Clinic has converted completely to an EMR system as of July 2004 and has been using medical records in research for more than 80 years. Its system currently has 6.5 million patient records collected systematically and electronically indexed. In addition, more than 17 million clinical notes are retrievable online. Mayo conducts more than 4,000 clinical trials each year, and many trials rely on information from medical records, primarily to identify potential research subjects.

The original goal was to develop an information system that would allow Mayo Clinic investigators to quickly identify potential participants for clinical trials. It functions over a highly secure interface with all user access screened by an approved Mayo IRB so that patient privacy and confidentiality are ensured. All data are used with patient permission. More than 95 percent of Mayo patients allow their records and samples to be used for research.

According to Christopher Chute, Professor and Chair of Biomedical Informatics at Mayo, the clinic is trying to address problems across records involving the consistency and comparability of data. Says Chute, "no standards, no research."

But like all institutions trying to meld medical records with research, the level of granularity and protocol-specific information currently available in the record is insufficient. In addition, the integrity and completeness of the record is paramount. Are all important data reflected—including medication history, immunizations,

pathology, radiology, and laboratory reports, as well as nonsystem encounters? According to Chute, cultural and organizational barriers also must be overcome. For example:

- Who owns the record?
- What happens when a patient moves or seeks care from another institution?
- What happens when institutions merge or close?

Chute says that to date, Mayo's medical records are most commonly used to study empirical outcomes and best practices.

However, Mayo is extending its expertise in the area of electronic records. In collaboration with IBM it is developing the Mayo Clinic Life Sciences System, which will house data from five existing Mayo clinical and patient databases. Eventually, the data sources will expand to include a bioinformatics resource comprised of clinical notes, Mayo's growing bank of genomics data, links to Mayo's existing tissue and serum repositories, the surgical index, and pathology records. Potentially, it could include comparable information from Mayo's Scottsdale, Arizona and Jacksonville, Florida locations. One unified, cross-referencing system will allow accurate and immediate access to millions of records that could aid in discoveries and, in turn, enhance patient care.

Researchers from IBM and the Mayo Clinic are using Blue Gene supercomputing technology and applying customized algorithms, data mining, and pattern recognition to uncover correlations between particular proteins, genetic markers, patient outcomes, and other factors that could lead to new diagnostics and treatments. This system will support data input, real-time synchronization with the EMR, Natural Language Processing (NLP), annotated patient notes, real-time identification and notification of eligible patients, and enrollment tracking.[20]

It is anticipated that by the end of the decade, Mayo doctors will be able to use clinical decision support and other electronic tools to tap into this evolving medical knowledge to make treatment decisions that are more likely to lead to positive outcomes.

The key feature of the application is its clinical notes feature that stores and sorts information of interest for clinicians and investigators. The system contains demographics, diagnostics, test results, clinical notes, and a microarray capability for all patients who have provided informed consent. The application links to PubMed[21] for searches to identify articles about genes of interest that were identified during analysis of genomic data. The system allows free as well as concept-based text searches. Security and confidentiality features include automated verification of user authentication and authorization, complete audit trail capture, and verification of whether the user has IRB approval and has completed HIPAA compliance training.

Regenstrief Institute: Indiana University School of Medicine

Over the past three decades, Regenstrief Institute research scientists have been developing the Regenstrief Medical Records System (RMRS), one of the nation's first EMR systems and the keystone of many institute activities. In addition to being a critical research tool, RMRS serves as the day-to-day EMR system at Wishard Hospital and its community clinics. With support from the National Library of Medicine, Regenstrief's informaticians have created the nation's only citywide EMR system, which currently allows physicians in the emergency departments, with the patient's permission, to view as a single virtual record all previous care at any of 11 hospitals. RMRS has been widely recognized for its role in improving quality of care, increasing the efficiency of healthcare delivery, preventing medical errors, and enhancing patient safety.

Regenstrief staff report that EMRs have been useful for prospective, retrospective, epidemiological, longitudinal, and cohort studies, and for enhancing clinical trials data.

They also report that EMRs may not be as useful for studying certain public health issues (e.g., obesity), because records systems lack information on critical aspects of the community outside the purview of medical records (e.g., activity levels, information on school foods).

Geisinger Health System: Danville, Pennsylvania

The primary purpose of Geisinger Health System's EMR system is to improve patient care. Geisinger provides care to more than two million patients in central and western Pennsylvania and is in the process of adapting its information technology systems for research purposes. Two personalized healthcare pilot tests are in place to test the ability to combine research with patient care. The pilot programs are initially aimed at improving care for two sets of patients: those with chronic heart disease and young children with suspected autism.

As part of the personalized health process, patients will fill out a questionnaire, which is an online interactive self-assessment form. The questionnaire will ask about health conditions and lifestyle issues related to smoking, weight, and eating habits. That information will be fed into an Epic Systems software database, which will allow a doctor to perform a risk assessment to determine, for example, the disease risk factors for a patient who smokes, has high cholesterol, or is overweight. Although the immediate goals of this project are to improve patient care, Geisinger officials anticipate that eventually this information could be used as evidence to be applied to broader clinical care. That is, in the aggregate, the results of the exercise could provide important evidence that could be generalized to larger patient populations.

Kaiser EMR System: KP HealthConnect in California

In February 2003, Kaiser announced plans for a new records system, KP HealthConnect, using Epic Systems software and technology services. This is a $3 billion investment to automate records for its 8.4 million members in eight regions serving nine states and Washington, DC.[22] It will integrate patients' clinical medical records with appointment scheduling, registration, and billing systems across all of Kaiser's regions.

When the system is complete it will provide the ability for Kaiser physicians to have instant access to patients' medical records; e-messaging capability; computerized order entry; e-prescribing; and treatment guidelines and alerts regarding incorrect medication dosage or dangerous interactions. System alerts will catch abnormal results, negative trends, chronic problems, and dangerous drug and procedure combinations. In the future, patients will be able to access parts of their records online, including test results, immunization history, and current medications. Patients will be able to book appointments, make payments, and send messages to their doctors. The system also will create standardized data for quality improvement efforts and performance benchmarks once it is running.

A large part of the system is administrative and will integrate appointment scheduling, registration, and billing functions. During the collaborative build, Kaiser had to deal with some 250 care support systems across the entire organization and develop standard data definitions for HealthConnect.

Dean Sittig, Director of Applied Research in Medical Informatics at Kaiser's Northwest Permanente Medical Group reported that there are almost half a million active patients/members in Northwest Permanente and that Kaiser has a transactional system for patient care and a data warehouse with extracted data for use by researchers. Research queries are never run against the transactional system.

He noted that a major challenge for the research community is learning how to conduct exploratory data analysis with such databases, rather than relying solely on human intelligence to run a query. ***Currently the computer cannot generate queries on its own, but Sittig envisions a time when a program can be developed to note patterns and trends of interest.*** And like other institutions, Kaiser Permanente is struggling with the need for NLP to capture the 50 to 80 percent of the patient record that is unstructured.

Some of the ways Dr. Sittig envisions using the data warehouse being built by Kaiser include:

1. ***Planning studies:*** estimating the number of patients with a given condition that are available in the patient population.
2. ***Building complex physiologic or patient care models:*** using clinical data to estimate the prevalence of various conditions and various rates of complications.
3. ***Identifying potential study participants:*** running queries of the database to find all patients who match the inclusion and exclusion criteria of the study being proposed.
4. ***Developing outcome reports for clinicians:*** using this information to feed information back to clinicians on various intermediate process measures or actual health outcomes.
5. ***Creating an intervention (e.g., a disease management program):*** using this database to identify patients in various disease states or with specific parameters who are eligible for specific treatments or tests. This list of patients would then be transferred to

20 At the Cleveland Clinic, IBM technologies are being used in a similar project to develop a translational medicine platform or an infrastructure that ties together patients' electronic health records with the Cleveland Clinic's clinical, genetic, and other research data. The clinic is using IBM Healthcare and Life Sciences Clinical Genomics Solution, which combines IBM technology, applications, industry expertise, and best practices.

21 See www.pubmed.gov.

22 See iHealthBeat, September 10, 2004.

the clinical information system so it can notify the appropriate clinicians or automatically call, send e-mail, or send ground mail reminders to patients.

6 ***Conducting post-marketing surveillance studies:*** identifying patients who received certain medications or combinations of medications or specific procedures and looking for increases in the incidence of adverse events or outcomes.

7 ***Combining clinical data with genomics data to identify genetic factors of disease:*** adding genomics data to current phenotypes data to begin unraveling the human genome.

8 ***Mining data in an attempt to identify possible errors or best practices:*** using various exploratory data and analytic techniques in an attempt to elucidate previously unknown or undocumented patterns in the data.

9 ***Providing insight into the effectiveness or efficiency of various interventions with respect to various disease states:*** for example, diabetes, or care locations (e.g., all patients admitted to the intensive care unit).

Primary Focus: Clinical Care in Public Settings

Indian Health Service: Department of Health and Human Services

The Indian Health Service (IHS) has long been a pioneer in using computer technology to capture clinical and public health data. The Resource and Patient Management System (RPMS) was developed in the 1970s, and many IHS facilities have access to decades of personal health information and epidemiological data for local populations. The primary clinical component of RPMS, the Patient Care Component (PCC), was developed by the early 1980s. The PCC contains an electronic abstract of patient information rather than a complete electronic healthcare record. It permits capture of the most essential clinical data concerning patient contacts with the healthcare system. IHS currently is bringing RPMS to the next level of clinical technology, the IHS Electronic Health Record (IHS EHR).

According to Howard Hayes, Director of the IHS EHR program, it is important to understand the architecture of the IHS EHR, which is a graphical user interface that overlies the legacy clinical information systems applications, collectively called RPMS. With a few exceptions, the EHR will not be generating new types of data, but will be feeding data into an existing database that in some locations has been populated for as long as 20 years.

In contrast to the private sector, the IHS focus has been on clinical data, which has emerged only recently as a priority, rather than payment information. Depending on when and how fully RPMS has been utilized over the years, local databases are already rich with a decade or more of clinical and administrative information. Moreover, IHS has a national data repository that accepts exports from other sites and is evolving into a true National Data Warehouse (NDW) (for further discussion of data warehouses, see the end of this section). The NDW project will upgrade IHS's national data repository, the National Patient Information Reporting System, to a new, state-of-the-art, enterprise-wide data warehouse environment.

IHS has a number of tools that are used to query local databases, and one of its priorities in EHR development has been to ensure that the integrity of the databases and the ability to query them is preserved. On a national level, the NDW will offer a number of standard and customized data marts for appropriately qualified users. The data include demographic data; third-party eligibility information; patient-based clinical data (e.g., health factors); and encounter-based clinical data (e.g., purpose of visit, procedures, medications, laboratory test results, radiological results). Historical records of changes in these data are maintained so that information about past as well as current circumstances can be obtained.

Information will be retrieved from the NDW via reports and ad hoc database searches. Internal users and selected authorized external users of the NDW will have access to more structured and specific subsets of this information (data marts), appropriate to their approved need and access. Because these data marts need not be permanent and their entire data can be refreshed, if required, from the permanent record contained in the data warehouse database, they can be highly user definable and adaptable, containing, for example, transformed or aggregated data that may be deleted, modified, or replaced. Because of their relatively smaller size and their simpler structure, search efficiency will be optimized, and data can be readily available to authorized users.

Hayes notes that research in Indian country entails an additional layer of complexity, because of the need to be sensitive about and responsive to the interests of tribes. Tribal participation in and approval of any research or publication is crucial, and IHS tries to protect both researchers and tribes from difficulties that can arise if this is not understood. However, IHS facilities are active in many types of clinical research, often in collaboration with universities or government agencies. How the EHR will impact that remains to be seen, but research, other than improvement of data quality, has not been a focus of the EHR development effort to date.

Veterans Health Administration: Department of Veterans Affairs

All VHA medical centers have EMRs. The daily volume of these systems includes more than 510,000 progress notes, discharge summaries, and reports, more than 860,000 orders, approximately 340,000 images, and more than 580,000 medications. Although VHA's computerized record activity began in the late 1970s, it has evolved over time to become VistA, VHA's current health information system.

As a consequence of VA's comprehensive use of medical information technology, a wide variety of electronic databases have been created, many of which include patient-specific clinical information that could be used for research purposes.[23] VA researchers routinely access these databases as well as patient records (with consent) primarily to conduct health services research. All internal VA requests for data stored in the VHA databases publicized in this monograph are assessed by the responsible program office and reviewed by the data steward for the database, and possibly the VHA Privacy Officer, on a case-by-case basis. Once approved the requests are sent to the physical location of the database for the database's custodian's attention. All requests from sources external to the VA for data stored in the VHA databases are subject to the regulations of the Freedom of Information Act (FOIA). Under FOIA, certain records may be withheld in whole or in part from the requestor if they fall within one of nine FOIA exemptions.

If funding and authorization are provided, VA plans to fully replace VistA with HealtheVet, a Web-based system. The new architectural strategy would integrate a health data repository with registration systems, provider systems, management and financial systems, and information and education systems. ***The health data repository would create a true longitudinal healthcare record including data from VA and non-VA sources, supporting research and population analyses, improving data quality and security, and facilitating patient access to data and health information***. A secure patient portal known as My HealtheVet would provide patients with access to their personal health records, online health assessment tools, mechanisms for prescription refills and making appointments, and access to high-quality consumer health information.

Although deployed nationally, a major barrier to the complete penetration of HealtheVet at every VA site is the challenge of the lack of an adequate high-speed telecommunications infrastructure in the more remote and rural parts of the country.

VistA is bringing the benefit of its long history of expertise with EMRs to a wider audience through the creation of VistA-Office, a free software package for use by small, private-sector healthcare providers, which should be available in late 2005.

Primary Focus: Research

A Clinical Care/Research Hybrid: The CHORUS Database on Patient Clinical Care

Some patient databases are being constructed specifically for combined clinical care and research purposes. For example, CHORUS (Collaborations in HIV Outcomes Research/United States) is a research database enrolling about 6,000 patients in four major U.S. HIV practices; more than 4,000 have volunteered already. This longitudinal study does not change treatment in any way, nor does it require additional doctor visits; instead, when patients give consent, the data generated during their regular medical care are also recorded anonymously for research. In addition, patients fill out a quarterly questionnaire. They can withdraw from the database at any time.

CHORUS is funded by Glaxo Wellcome, Inc., but an independent scientific board of physicians and other HIV experts, including community advocates, decides what

23 See www.virec.research.med.va.gov/index.htm.

research is conducted and published. Database housing and management is provided by Research Triangle Institute of Research Triangle Park, North Carolina.

With CHORUS, medical records are maintained by computer. At the end of each day, new information about the patients who have consented to enter the program is copied on an "anonymized" form, using a unique identifier without the patient's name or other identifying information. All CHORUS data, identified by this number, are transmitted securely to Research Triangle Institute and added to the database. The research data can be analyzed by site (for each of the four sites), but individuals cannot be identified.

Steven Becker of Pacific Horizon Medical Group is co-chair of the CHORUS scientific advisory committee. Becker believes that observational databases will become increasingly useful in understanding HIV disease as well as in answering many other clinical questions.[24]

The observational data collected through programs such as CHORUS are important because of the limitations of conducting randomized clinical trials. Because observational trials record real-world experience, they reflect prevailing medical practice and could be more likely to uncover treatment approaches that are realistic and feasible.

The General Practice Research Database

The United Kingdom's General Practice Research Database (GPRD) is the world's largest computerized database of anonymized longitudinal medical records collected from primary care.[25] Currently, data are being collected on more than three million active patients (approximately nine million total) from almost 2,000 general practitioners in 400 primary care practices throughout the United Kingdom. The data are updated once every two weeks. Containing comprehensive observational data from clinical practice, the GPRD is a valuable tool for academic research in a broad range of areas, including clinical epidemiology, disease patterns, disease management, outcomes research, and drug utilization. More than 400 research papers have been published using the database.

Patient records are downloaded directly from participating general practices that are paid a small fee for supplying the data. Patients are allocated a unique identification number; name and address are not collected. Variables collected include practice and patient registration details; demographics, including age and sex of patient; medical diagnosis; all prescriptions, including repeats; events leading to withdrawal of a drug or treatment; referrals to specialists and hospitals; treatment outcomes, including hospital discharge reports; and miscellaneous patient care information (e.g., smoking status, height, weight, immunizations, laboratory results).

Some of the problems that plague all practice databases plague the GPRD. For example, diagnostic criteria cannot be described in great detail and must be accepted as the best diagnostic formulation. There are also the inevitable variations in physician perceptions—for example, one doctor's dyspepsia might be another's reflux esophagitis. In addition, the database contains only the information that general practitioners normally require; for example, occupation or employment status is not available, although they could be requested.[26]

There have been several validation studies of the GPRD confirming that the quality and completeness of the computer-recorded data are high.

The database may be used only for medical and health research purposes on a nonprofit-making basis. It is managed by the GPRD Division of the Medicines and Healthcare products Regulatory Agency (MHRA), the United Kingdom's medicines and devices regulator, and receives no funding from the United Kingdom Department of Health. Data may be accessed by purchasing a license.

Patient Data Warehouses

The term "data warehouse" refers to a set of technology tools and processes used to gather information from source information systems, cleanse and catalog this information, store it in a retrievable format, and enable reporting. The information in the warehouse is a pool of data extracted at a point in time from transactional or production systems. While transactional systems are used in daily operations by a large group of staff, data warehouses are accessed by a small and discrete group of users who do not enter data into the system but query it for interpretation or analysis.[27]

Functionally, the data warehouse integrates operational and historical data from multiple, disparate data sources across the enterprise and preserves them. By joining these scattered data fragments, users can employ the stored data for clinical and administrative decisionmaking, and, ultimately, for the future well-being of patients and the institution.

Important features, such as confidentiality of data, make data warehousing for disease management and research a unique application of the technology. For example, in scanning patient pharmacy records it is important to know whether any of the patients have given permission to use their records in a study that is attempting to correlate medications with conditions. In addition, gathering data from a variety of sources, such as insurance claims, pharmacy records, healthcare provider reports, and laboratory results, can be complicated by information presented in wildly different formats. The raw data must be expunged of unnecessary and incorrect items and stored in a single standard format.

Creating data warehouses presents many of the same challenges as creating databases of EMRs. Nonetheless, several universities are working on creating patient data warehouses, including the University of Michigan, the University of Pittsburgh, Massachusetts General Hospital, and Brigham and Women's Hospital.

Directory of Clinical Databases: DoCDat

The London School of Hygiene & Tropical Medicine's online Directory of Clinical Databases, DoCDat, was established to provide a directory of clinical databases in the United Kingdom, along with up-to-date information on those databases, in order to enable greater access to and use of existing clinical databases and to improve their quality. DoCDat provides independent evidence regarding their uses and limitations.[28]

DoCDat receives financial support from the National Centre for Health Outcomes Development, which is funded by the Department of Health. It is a free research resource for all who are involved in clinical quality, clinical governance, and health services management and research, including policymakers, researchers, clinical audit teams, clinical governance specialists, health services researchers, public health practitioners and clinicians, and others. The service can be used to determine which clinical databases exist in the United Kingdom and to obtain for each database a brief description and information about how it is managed, as well as an assessment of its scope and quality, including coverage and accuracy. Those who use DoCDat can identify databases quickly and inexpensively that may be appropriate for their efforts in evaluative research and clinical audit, in supporting shared decisionmaking models, or for strategic planning of services.

The database can be searched in three ways: by defining categories, such as body system, pathogenesis, intervention, age group, and country; by specifying topic or database; or by viewing the complete list of all databases in the directory. Histograms can be generated that provide comparisons between the data quality of different databases (comparative summary histograms).

Each database has been reviewed for quality with a structured questionnaire developed by a national interdisciplinary expert group of clinicians, epidemiologists, statisticians, and information specialists that covers its general aspects, such as when it was established, who it includes, and what geographical area it covers. Other information that is gathered about each dataset includes the number of individuals covered, data linkage, data security, patient confidentiality, frequency of standard audit reports, a bibliography of published work, who manages and runs the database, who funds it, data quality information, a copy of the data collection questionnaire, and contact details.

DoCDat does not provide the actual data from the databases or guarantee access to the data, and each database remains subject to its own procedures, rules, and regulations for use. Contact information is provided to help a potential user find out more from the database custodians. The overview of the databases that DoCDat provides is based on an independent assessment and not on the views of the database custodians. The DoCDat Web site includes the criteria that are used currently to assess quality.

DoCDat covers databases that have information on the actual or potential recipients of healthcare. It does not cover databases that are limited to the provision of resources or services. The service focuses primarily on databases that contain information about individuals and that centrally collate the data collected from different healthcare providers. They must meet the following criteria:

1 ***Inclusion in the database is defined by a common circumstance***, for example, the individual's

24 See www.aids.org/atrv/a-301-01.html.
25 See www.gprd.com/intro/default.asp.
26 Walley T, Mantgani A, "The UK General Practice Research Database," *Lancet*, 1997;350:1097-1099.
27 See www.himss.org/content/files/proceedings/2000/sessions/ses104.pdf.
28 See www.docdat.org.

condition, the intervention required or undergone (which might be a diagnostic test, treatment, or a collection of interventions), an administrative arrangement (such as a subscriber to health insurance, target for immunization), or an adverse outcome. Cohorts defined by behavior or environmental exposure are excluded.

2 ***Provides individual-level data***, whether or not users of the database are permitted to know the identity of the individuals. It focuses primarily on centralized individual-level databases, based either on prospectively or retrospectively collected data.

3 ***Includes data from more than one provider of healthcare*** (usually many providers in a region or country). Single-provider databases may be included if they cover an area of healthcare for which there are no multiprovider databases.

DoCDat also includes limited information on two other types of databases:

- ***Noncentralized individual-level databases*** in which the same dataset is collected by more than one provider, but the data are not collated centrally.
- ***Aggregated databases*** that collect data about groups of people rather than about individuals.

Limited information also is provided on databases that have not been completely assessed by DoCDat, which includes contact details for the database custodian.

DoCDat is adding more databases to the directory and also works to update and maintain the current entries by requesting information regarding changes from the database custodians. DocDat also provides to custodians advice about methodological issues related to improving database quality, when appropriate, by putting database custodians in contact with one another so that they can share practical experiences.

The Partners HealthCare Research Patient Data Registry

The Partners HealthCare Research Patient Data Registry (RPDR) is a data repository of information on two million Massachusetts General Hospital and Brigham and Women's Hospital patients accumulated since the 1980s. RPDR, first tested as a prototype in 1997, is a centralized clinical data registry, or data warehouse. The RPDR gathers data from various hospital legacy systems and stores it in one place. It brings clinical information to the researcher's fingertips and ensures the security of patient information by controlling and auditing the distribution of patient data within the guidelines of the IRB and with the use of several built-in, automated security measures.

The RPDR stores 500 million diagnoses, medications, procedures, reports, and laboratory values with demographic and encounter information. More than 1,000 authorized clinicians query it to select research cohorts and to elicit trends in disease incidence and progression. Although it contains a massive amount of text-based data, it cannot yet be correlated with radiologic or other images, which would quickly overwhelm it.

Instead, a new integration prototype was developed to allow a researcher to see the images associated with a report by seamlessly invoking a Web viewer. Cohorts can be selected based on imaging characteristics not captured in the report. Disease trends can be found and traced in radiologic images.

The RPDR brings clinical information to researchers in two ways: first, researchers can get access to data via the RPDR online query tool to obtain aggregate data, such as total patients with user-defined diagnoses, procedures, or medications, during a particular time frame. Then, with proper IRB approval, researchers can request more detailed medical record data on the user-defined group, such as demographics, contact data, and discharge summaries.

According to Shawn Murphy, RPDR Director, the RPDR has achieved its initial goal of finding cohorts for clinical research. Increasingly, however, clinical investigators at the institution are requesting data for research purposes. "This poses a challenge," said Murphy, "because the repository lacks the specificity needed for clinical research." Although sensitivity tends to be good, the lack of specificity currently limits its use.

Many believe the RPDR is likely to serve as a good first model for "best practices" in the whole field of medical informatics and research data mining. The RPDR has a number of significant technical and procedural features that make it better than the more commercial offerings as a potential research tool. Its operations are tightly integrated with an IRB, and the data available to researchers are filtered with two-way anonymization as they are included in the system, so that records can be searched with identifiable patient data when necessary, pending IRB approval.

The data included can be searched using diagnoses, inpatient procedures, demographics, inpatient medications, and provider type data, and queries can be stored so that they can be repeated, modified, or aggregated to meet a research project's needs.

The system is generally accessible via standard Internet protocols—data can be uploaded by FTP, and results can presumably be made available the same way. It appears that the actual searches and queries must be done by researchers onsite using workstations on one of the participating institutions' local networks to access the software, which runs centrally. This is a good security and technical model, and there are a number of ways this could be extended (securely) to include other institutions and partners for data sources.

RPDR investigators are currently exploring ways to make the database available through secure methods to external users. They also have a Cooperative Agreement with NIH's National Center for Biomedical Computing to test the feasibility of exporting the program to other institutions.

The National Institutes of Health's Roadmap

The National Institutes of Health (NIH) is the federal agency most focused on the use of electronic clinical data for the purposes of research. In addition to supporting numerous clinical studies that rely on an EMR or partial clinical dataset for research, NIH has provided more than $128 million for development and research related to "clinical research networks." The Clinical Research Networks piece of NIH's *Re-engineering the Clinical Research Enterprise Roadmap* will promote and expand clinical research networks that can rapidly conduct high-quality clinical studies that address multiple research questions. An inventory of existing clinical research networks will explore existing informatics and training infrastructures in order to identify characteristics that promote or inhibit successful network interactivity, productivity and expansion, or broadening of research scope.

The results of the inventory and a number of feasibility studies will assist in the development of a National Electronic Clinical Trials and Research (NECTAR) network, which will provide the informatics infrastructure that will serve as the backbone for interconnected and interoperable research networks.

NIH intends to make the data broadly available to researchers for use in selecting networks for clinical studies, and the information captured in this inventory will be made available in an electronic inventory database. The inventory will include public and private networks, including those engaged in international research and focused on research with underserved populations. It will also include entities focused on defined populations; those organized by locus of care or by different types of healthcare providers, such as nurse practitioners or psychologists; and disease-specific specialty groups.

However, according to Kenneth Buetow, Director of Bioinformatics at NIH's National Cancer Institute, although it is anticipated that the inventory will be fairly comprehensive, it will capture only approximately five percent of the U.S. patient population—that is, those individuals who are already involved in clinical trials, not the typical practice population. The focus of this report is the vast larger resource—the clinical data collected in the course of routine patient care and entered into an electronic record.

EMR Systems: Follow the Leaders

The initiatives described in this section highlight the enterprising nature of individuals and institutions that understand the value of systematically collected, stored, and accessible patient data. They range from efforts to make the best use of legacy systems to programs created specifically to harness clinical data in real time. They also illustrate that biology is becoming an information science, requiring new collaborations among clinical medicine, biology, and the fields of bioinformatics, computer science, and mathematics.

Investigators at institutions that have developed the capability and permission to search their patient databases for informative patients and families will be well positioned to exploit the knowledge arising from genomics and proteomics research. EMRs and clinical databases and warehouses can make the work of specialists in one discipline widely accessible to specialists in many disciplines.

IV. What Is the Tipping Point for EMR System Adoption?

One of the greatest obstacles to the use of clinical data in research is the low level of adoption of EMR systems across the United States. In this section, we describe the current status of EMR adoption and the many challenges the healthcare system faces in moving toward a system that both improves patient care and facilitates research.

Although many industries, such as banking and insurance, have embraced information technology and the benefits it offers, healthcare in many respects continues to lag behind in this critical area.

Growing Investment in EMR Systems

In the healthcare arena, the average investment in information technology computer hardware, software, and services is only about $3,000 annually for each worker, compared with $7,000 per worker on average for private industry and nearly $15,000 per worker in banking.[29]

Yet at this time, the cost of at least one component of healthcare information technology—EMR systems—appears to be falling, and there is an increasing focus on the part of the federal and state governments, healthcare providers and organizations, and consumers on the many ways in which EMRs can improve care and save money.[30]

The future is not so hard to predict. It's already here. It's just not equally distributed. **Futurist William Gibson**

So, is a critical mass close to being reached in the adoption of EMRs that will spur more widespread use of such systems and information technology in healthcare generally in this country?

Although statistics vary somewhat regarding the adoption rates of EMR systems, most point to low but growing rates on the part of physicians and hospitals, with one estimate indicating that 14 to 28 percent of doctors' offices have EMR systems (with larger practices tending to be more likely to adopt one than smaller practices).[31,32] Although more hospitals are adopting EMR systems, it is estimated that overall only 13 percent have one.[33]

The implications are significant, because healthcare remains a fragmented industry, with an estimated 60 percent of physicians practicing in offices with 10 or fewer physicians and 35 percent in offices with three or fewer physicians.[34] The reasons for these low adoption rates range from cost to difficulties in modifying clinical workflow and decisionmaking processes to a variety of technical and system compatibility issues, as well as issues surrounding security and privacy.

29 Lohr S, "Health Industry Under Pressure to Computerize," *New York Times*, February 19, 2005.
30 American Academy of Family Physicians Center for Health Information Technology, *Partners for Patients Electronic Health Record Market Survey*, 2005, www.centerforhit.org/PreBuilt/chit_2005p4pvendsurv.pdf.
31 Holmes A, "The Slow Road to Electronic Records," *CIO Magazine*, October 15, 2004, www.cio.com/archive/101504/healthcare.html.
32 Broder C, "Government Seeks Way to Integrate Standards Process, Healthcare IT News," March 7, 2005, www.healthcareitnews.com/NewsArticleView.aspx?ContentID=2565; Audet A et al., "Information Technologies: When Will They Make It Into Physicians' Black Bags?" *MedGenMed*, 2004;6(4), www.medscape.com/viewarticle/493210_print. This article also discusses the cost barrier. "The most significant barrier to use of IT systems by U.S. physicians is their cost, and the financial barriers are greatest for solo and small-group practices. The initial costs of acquiring EMR capability have been estimated at $15,000 to $50,000 per physician….Practice size appears to be the predominant factor affecting use of IT." Data were from the 2003 Commonwealth Fund National Survey of Physicians and Quality of Care, administered between March and May 2003 to 3,598 U.S. physicians randomly selected from an American Medical Association list. Also see www.ihealthbeat.org/index.cfm?Action=dspItem&itemID=107821.
33 Pettey SM, "Government Promotes Application of Information Technology to Health Care," *Caring for the Ages*, 2004;5(12):6-8, www.amda.com/caring/december2004/publicpolicy.htm.
34 Lohr S, "Health Industry Under Pressure to Computerize," *New York Times*, February 19, 2005.

Despite the hurdles, rates of adoption may be growing, however, and many expect growth to increase significantly in the near future. For example, although only 18 percent of respondents in a Healthcare Information and Management Systems Society (HIMSS) survey of 253 information officers representing 550 hospitals report a fully operational EMR in place at their organization, nearly two-thirds indicated they have either developed a plan to implement an EMR system or they have begun to install EMR hardware and software, and more than half of U.S. hospitals plan to add EMRs in the next two years.[35]

David Bates, Chief of Internal Medicine at Brigham and Women's Hospital, Boston, and a patient care EMR expert, predicts that 70 to 80 percent of all hospitals and 50 to 60 percent of all physicians will have EMRs within five years.[36]

Increasing numbers of physician practices, hospitals, and health systems are also adopting EMR systems. Large private health systems that have made multibillion dollar technology investments in EMR systems include Kaiser Permanente, the Mayo Clinic, the Henry Ford Health System, the Regenstrief Institute, and Sutter Health.

The Enormity of Building a Network Infrastructure

The National Health Information Network

The NHIN is a federal government initiative for widespread deployment of health information technology in the United States throughout the public and private sectors within the next decade.[37] Its goal is a comprehensive knowledge-based network of interoperable systems of clinical, public health, and personal health information that would improve medical care and decisionmaking by allowing healthcare providers access to up-to-date electronic health records for patients who have authorized it, whenever and wherever the patient receives care.[38]

The federal government is working to standardize its own healthcare information systems in part "to provide a rallying point for private industry" to adopt EMR technology.[39] In fact, much of the momentum that has been occurring in the adoption of the electronic EMR has been spurred on by a number of federal government agencies that have created electronic systems for improving patient care, claims processing, and payment.

EMR systems already are in place in several large federal government agencies, including the Department of Health and Human Services (HHS), the Indian Health Service (IHS), and the Department of Veterans Affairs (VA) (see Appendix D). The Consolidated Health Informatics initiative seeks to apply common standards to all agencies in the federal health enterprise.

State and Regional Efforts

It will be important for states and other entities to get involved, because the overall level of federal funding for health information technology development is low. Dr. David J. Brailer, National Coordinator for Health Information Technology at HHS, has indicated that support on the part of governors is essential to the implementation of nationwide EMRs and urged them to support an open health information network that would allow Internet-based prescriptions and treatment decisions.[40] Many EMR system development efforts have already emerged at the state level through various initiatives (see Appendix E for examples), often in the form of collaborations between, for example, payers and states to move forward in creating statewide EMR systems.

Regional Health Information Organizations (RHIOs) are becoming an important strategy in accelerating the plan for the adoption of healthcare information technology and EMRs. RHIOs will enable data exchange in a region by tying together local networks, and they also will help to encourage the adoption of healthcare information technology among providers.

35 *16th Annual HIMSS Leadership Survey*, February 14, 2005, www.himssconferencenews.org/deliver_file.php?sid=S200502141622017XZBH5&omk=1007&file=1057&image=.
36 "Between You, the Doctor, and the PC," *BusinessWeek Online*, January 31, 2005, businessweek.com/magazine/content/05_05/b3918155_mz070.htm.
37 See Pettey, "Government Promotes Application of Information Technology to Health Care," and Holmes A, "The Slow Road to Electronic Records," *CIO Magazine*, October 15, 2004, www.cio.com/archive/101504/healthcare.html. Also see McKesson Corporation. *Five Years Later: A McKesson Perspective on the IOM Report Anniversary*, 2004.
38 See aspe.hhs.gov/sp/NHII/FAQ.html.
39 Ibid.
40 See www.ihealthbeat.org/index.cfm?Action=dspItem&itemID=109393.

What Are the Barriers to EMR System Adoption?

Significant implementation issues and challenges continue to face the widespread adoption of EMR systems and the eventual development of a comprehensive national EMR system, as well as the benefits that would derive from a national system. The challenges ahead include:

- cost (as related to the development of a national system and to adoption by practices and health systems);
- security and privacy issues;
- acceptance and training;
- infrastructure development; and
- technical issues.

For Some, the Investment Is Not Worth the Expense

Cost is a barrier to adoption at the health system and practice levels, with the burden weighing most heavily on smaller practices. Even though the cost of adopting an EMR system, which is still a primary barrier to adoption, is falling, the transition from pre-1990s proprietary technology to new integrated systems and new technologies is still expensive.

Capital costs, including upfront financial expenditures, are perceived as the greatest primary barriers to EMR system implementation, and access to capital is a significant issue.[41] Significant start-up funds are required for software and hardware, and there are initial and ongoing costs for training staff in their use, as well as for support and expansion.

Yet falling prices for personal computers and software and the increasing growth and role of the Internet in recent years have brought down the cost of adopting EMRs and have made it easier to connect to specialists, hospitals, and insurers. An American Academy of Family Physicians Center for Health Information Technology vendor survey revealed that ownership costs of an EMR for small practices is approaching affordability and that EMR companies' growth in 2004 was substantial. In fact, the cost fell below the $10,000 per physician per year threshold that many experts said needed to be crossed to ensure widespread adoption of EMRs.[42]

The survey found that an integrated electronic records and practice management system cost an average of $7,232 per physician in 2004. An individual record system cost $5,537, and an individual practice management system cost $4,189.[43]

There is still enormous variation in cost though, especially when factoring in the expense of hardware, software, and time lost caring for patients while learning the system, with the cost of an EMR system estimated by some to be as high as $30,000, which is prohibitively expensive for most physicians.[44]

Financial support for information technology also continues to be an issue for healthcare information technology executives. ***In one survey of these executives, 20 percent of respondents cited lack of adequate financial support as the most significant barrier to successfully implementing information technology at their organization***.[45]

Some expect that greater use of incentives will help, especially when Medicare defines how it will encourage adoption through payments, and private incentive programs are growing. One group estimates that to spur adoption of EMRs by small- and medium-sized practices, payers must cover most of the initial cost by offering $12,000 to $24,000 per full-time physician.[46]

The Centers for Medicare and Medicaid Services has announced a pilot program that will award bonus payments to some physicians if they provide better care and reduce costs for patients with certain conditions. One of the tools they will use to improve care is EMRs. This three-year Physician Group Practice program is Medicare's first pay-for-performance initiative for physicians.[47, 48]

41 See www.us.capgemini.com/news/current_news.asp?ID=427.
42 See www.centerforhit.org/PreBuilt/chit_2005p4pvendsurv.pdf for the Partners for Patients Electronic Health Record Market Survey, American Academy of Family Physicians Center for Health Information Technology, 2005. Also see www.ama-assn.org/amednews/2005/03/14/bisa0314.htm for some comments on low adoption rates and on the conventional wisdom that "until powerful EMRs sell for $10,000 or less per physician, demonstrate that they save time and money, or are mandated, physician adoption of the technology will continue to just move forward slowly."
43 See www.centerforhit.org/PreBuilt/chit_2005p4pvendsurv.pdf.
44 Lohr S, "Health Industry Under Pressure to Computerize," *New York Times*, February 19, 2005.
45 *16th Annual HIMSS Leadership Survey*, February 14, 2005, www.himssconferencenews.org/deliver_file.php?sid=S20050214162201 7XZBH5&omk=1007&file=1057&image=.
46 Connecting for Health—The Markle Foundation, Financial, *Legal and Organizational Approaches to Achieving Connectivity in Healthcare*, October 2004, www.connectingforhealth.org/assets/reports/flo_sustain_healtcare_rpt.pdf. Also see Havenstein H, "E-Health Records Slow to Catch On," *ComputerWorld*, February 21, 2005, www.computerworld.com/printthis/2005/0,4814,99905,00.html.
47 See the Centers for Medicare and Medicaid Services (CMS) announcement at www.cms.hhs.gov/media/press/release.asp?Counter=1341.
48 On another matter related to CMS and barriers to EMR adoption, see www.ihealthbeat.org/index.cfm?Action=dspItem&itemID=110322, where the following is reported: "CMS soon will announce regulations to exempt insurers from laws that prevent them from helping physicians adopt electronic prescribing software, CMS Deputy Administrator Leslie Norwalk said on Tuesday….Norwalk suggested that the measure might go beyond e-prescribing to offer 'safe harbor' for other types of information technology as well."

Cost will continue to remain a sensitive issue for many reasons. For example, an AMA poll has revealed that Medicare cuts could cause physicians to put off investments in their practices that could improve patient care, including investments in information technology such as EMRs.[49]

Physicians Are Skeptical of the Value of EMRs

On the physician and provider side there are concerns about how information technology may affect the care provider role and disrupt workflow. Other concerns include the increased time needed to enter data and the potential for a system to have limited usability at the point of care.[50] According to David Kibbe, Director of the Center for Health Information Technology of the American Academy of Family Physicians,

"The problem we're increasingly hearing from these doctors is that the whole is less than the sum of the parts. These are disaggregated, disconnected pieces of information technology, and increasingly what they want to have is an [electronic health record]—an integrated system into which the information and workflow components fit—so that they don't have to look at three different screens: one for lab results, one for patient records, and another for financials. They want them to be integrated in the same way that your financial records are integrated. When you go online for your banking, you don't have to log out to pay the bill after looking at your balance, and you don't have to remember another passcode."[51]

Consumers Are Concerned About Security Breaches

At this time, fears of unauthorized access to and use of EMR systems continue to be a significant barrier to EMR adoption. Ensuring the security and privacy of EMR systems remains a substantial challenge, one that will be central to continued system adoption, as there is little doubt that improved system security will help drive automation.

In a February 2005 Harris Interactive poll, three-quarters of respondents responded they believe that EMRs can improve the quality of care patients receive by reducing the number of redundant or unnecessary tests and procedures. Seventy-three percent of respondents also say that healthcare costs would be significantly reduced through the use of such records.[52] There are some concerns about EMRs though, especially in the areas of security and privacy.

The same February 2005 Harris Interactive Poll that suggested increased consumer acceptance of EMR technology also revealed that the number of U.S. adults who believe that their personal medical information has been disclosed improperly has fallen (from 27 percent in 1993 to 14 percent in 2005), indicating that new federal regulations to protect the privacy of medical records may be having a positive effect.[53]

However, these findings about security stand in stark contrast to the consternation that has surrounded recent reports of data theft, and the resulting possibility of identity theft, that has occurred in several industries, including medical care.[54] These reports have highlighted the real dangers of electronic storage of personal data, which may result in unauthorized use. These breeches have alarmed patient advocates regarding the potential for third-party organizations, such as employers and health insurance companies, to have increased access to patient information.[55]

Some privacy advocates say that a central national repository of patient data could be abused and targeted by anyone who infiltrates the system. Supporters of EMRs believe the systems are more secure than paper records because of the safeguards that can be built in, even though there is a greater potential to gain unauthorized access to a large number of files.[56]

Healthcare information technology executives also have concerns. According to the 16th annual HIMSS Leadership Survey, an internal breach of security continues to be the primary security concern identified by them. The majority of organizations use multiple

49 See Amednews.com item at www.ama-assn.org/amednews/2005/04/25/gvl10425.htm.
50 Jackson K, "What's Holding up the EMR? Barriers to the Universal Adoption of Electronic Medical Records," For the Record, 2004;16(4):30, www.fortherecordmag.com/archives/ftr_022304p30.shtml. Also see www.health-itworld.com/enews/09-09-2004_399.html for an account of a health information technology implementation that did not work out as intended at Cedars-Sinai Medical Center, which shut down its computerized physician order entry system.
51 Jackson K, "What's Holding Up the EMR? Barriers to the Universal Adoption of Electronic Medical Records," *For the Record*;16(4):30, www.fortherecordmag.com/archives/ftr_022304p30.shtml.
52 See www.harrisinteractive.com/news/newsletters/wsjhealthnews/WSJOnline_HI_Health-CarePoll2005vol4_iss04.pdf and www.harrisinteractive.com/news/allnewsbydate.asp?NewsID=895.
53 The survey also indicates that 71 percent of adults had not read or heard of EMRs and that of those who had heard of them, 48 percent think that benefits outweigh the risks to privacy, while 47 percent believe the risks outweigh the benefits. A large majority of 82 percent believe it is either very (45 percent) or somewhat (37 percent) important that patients will be able to track their own personal medical information in these electronic records.
54 For example, see www.ihealthbeat.org/index.cfm?Action=dspItem&itemID=109543, www.chron.com/cs/CDA/ssistory.mpl/front/3152953, and www.ihealthbeat.org/index.cfm?action=dspItem&itemID=110658&changedID=110601 for news stories on inappropriately revealed and stolen data.
55 Baker ML, "National Health Info Network Needs Safeguards," *eWeek*, February 7, 2005, www.eweek.com/article2/0,1759,1761542,00.asp.
56 "Between You, the Doctor, and the PC," *BusinessWeek Online*, January 31, 2005, businessweek.com/magazine/content/05_05/b3918155_mz070.htm.

technologies to secure their data. Seventy percent of respondents indicated they plan to implement single sign-on in the next two years, while currently only 21 percent of respondent facilities are using this tool.[57]

Technologies are available to build privacy and security into the health information infrastructure, through the following methods:

- employing effective user authentication techniques (including two-factor authentication methods);
- ensuring that only the data that needs to be released are released;
- restricting EMR viewing restricted to those with explicit permission in the medical community;
- segmenting data so that a patient's personal information is separated from his/her clinical information; and
- using biometrics in place of passwords.

Certainty of both a patient's identity and the user's identity is key, and a properly implemented system would have the capability of letting patients know who is accessing their information.[58] In the future it is possible that digital rights management systems, currently used in the entertainment industry, will be another way to protect patient privacy.

Importantly, the Health Insurance Portability and Accountability Act (HIPAA) of 1996, which involves the electronic standardization, security, and privacy of health information, is in some ways actually helping to drive EMR adoption by making automation of health information a more critical imperative.

Experience has shown that security is much easier to manage in a centralized database, where only one copy of a specific patient's record is kept. A system generally can be considered secure if the database is properly configured and the network is set up correctly, with some form of strong authentication and access control for record viewing and modification. Auditing controls and other periodic checks regarding access and attempted access are easier to implement and monitor when the data are centralized.

However, if patients and/or providers are keeping copies of their records on some kind of portable media, access and security issues multiply. For example, when a patient's information is stored in two or more places at the same time, because all copies of any specific health record need to be synchronized periodically, questions arise involving who would keep the master copy and how any new or changed data would be communicated to the central or "home" system. As is true of any form of electronic patient information, protections are needed to safeguard this data against loss, damage, hardware failures, intentional manipulation, and other events that could adversely affect the integrity of the records and make the data unreliable for patient use or for research.

Institutions Have to Make Big Changes in the Way They Do Business

Transitioning to an EMR system will require extensive changes in a healthcare organization's business processes, as well as in the computer hardware and software needed to support and run the EMR. Because medical providers and other users will need access to the EMR system at the point of service to the patient, most facilities will need to upgrade their network infrastructure and install new computer hardware. Significant start-up funds are required for software and hardware, and there are initial and ongoing costs for training staff in their use, as well as for support and expansion.

In moving toward integrated delivery systems in older hospitals/systems, legacy systems can be a problem. However, the adoption of common data standards will make the transferring of legacy data to a new system easier and more practical.[59]

Technical Issues Abound

The proprietary basis of many EMR products raises key issues regarding the interoperability of systems, including the need for standard underlying reference vocabularies and presentation formats for clinical data.[60] These will help address the lack of standardization of clinical data and messages. Standards for security and confidentiality also are needed. Much remains to be done, including addressing barriers to the adoption of open standards and open source software, which may present an important path forward.

Other significant technical issues related to implementing the EMR across the continuum of settings—ranging from smaller scale systems, to wider migrations, to large federated systems—involve data coding and data entry; the design and provision of effective user interfaces; effective database design; and the provision of data security. Overall, there is a need for flexible configuration management that will support extreme variations in process across healthcare settings.

At present, most EMR systems do not integrate with those of other vendors, and some systems offered by the same vendor are not even integrated with each other. Moreover, no two sites' implementations of any vendor's systems are the same. In short, little is designed or implemented to interoperate beyond a specific site or system implementation.[61]

Hardware and Software Issues

EMR adoption must be able to grow with the information technology and healthcare environment, including new technologies such as handheld devices, wireless communications, biometrics, continuous speech recognition, new imaging modalities, Web access, thin client-based ubiquitous connection, and personal health record support via the Internet. Interconnectivity of devices is required, including customized computer terminals, laptops, PDAs, pagers, cell phones, and more.

Problems involved with selecting an EMR product include difficulties in evaluating EMR system options; vendor transience; software that does not meet specifications, does not have adequate documentation, or does not achieve stated performance goals on the stated hardware requirements; problems with complex queries and indexes; server-related problems; and client PC software deployment issues.[62]

In general, the predominant software systems being deployed have an administrative and business orientation—for example, appointment scheduling, providing medication and treatment histories, and providing billing histories and the ability to link to external partners (pharmacies and specialty laboratories) for easier access and for sales and marketing purposes. Some systems are building in decision-support capabilities for providers and patients (e.g., reminders for prescription refills, routine tests, drug interaction warnings), but none have been constructed with research in mind.

The widespread use of open source software,[63] such as that used for the VA's VistA system, requires convincing vendors of proprietary systems that open source can be embraced without upsetting their interests. Open source software may provide a route for overcoming a number of barriers to EMR adoption, including cost, transient vendors, and lack of common data standards. It also reduces EMR ownership and development costs and lowers EMR prices.[64,65]

How Are the Barriers Being Addressed?

Many issues are being tackled through collaborative efforts. At the federal level, the Consolidated Health Informatics (CHI) initiative, which is a collaborative effort to embrace health information interoperability standards, has adopted 20 uniform standards for electronic exchange of clinical information to be used across the federal health enterprise.[66]

In addition, eight large technology companies—IBM, Microsoft, Intel, Oracle, Accenture, Cisco, Hewlett-Packard, and Computer Sciences—have formed an alliance and issued recommendations to the federal government on how to speed the development of a digital health network. The

57 *16th Annual HIMSS Leadership Survey*, February 14, 2005, www.himssconferencenews.org/deliver_file.php?sid=S200502141622017XZBH5&omk=1007&file=1057&image=.
58 "There are also some specific technical standards and best practices being developed in healthcare information security that will help to increase the confidence in digital identities." Jackson K, "What's Holding up the EMR? Barriers to the Universal Adoption of Electronic Medical Records," *For the Record*, 2004;16(4):30, www.fortherecordmag.com/archives/ftr_022304p30.shtml.
59 Bates DW et al., "A Proposal for Electronic Medical Records in U.S. Primary Care," *J Am Med Inform Assoc*, 2003;10(1):1-10, www.pubmedcentral.nih.gov/articlerender.fcgi?tool=pubmed&pubmedid=12509352.
60 The National Alliance for Health Information Technology has proposed a definition for the term "interoperability" and is seeking comment on it in an effort to help guide the movement toward interconnected clinical systems. It is defining interoperability as "the ability of different information technology systems, software applications and networks to communicate, to exchange data accurately, effectively and consistently, and to use the information that has been exchanged." See www.ihealthbeat.org/index.cfm?Action=dspItem&itemID=109814.
61 *Capgemini, Health Information Technology and the Electronic Health Record: Implications for Healthcare Organizations*, 2004, www.us.capgemini.com/downloadlibrary/files/Health_ElecMedRec04.pdf.
62 Tonnesen AS, LeMaistre A, Tucker D, *Electronic Medical Record Implementation Barriers Encountered During Implementation*, www.amia.org/pubs/symposia/D005401.pdf.
63 A program in which the source code is available to the general public for use and/or modification from its original design free of charge. Open source code is typically created as a collaborative effort in which programmers improve upon the code and share the changes within the community.
64 Kantor GS, Wilson WD, Midgley A, "Open-source Software and the Primary Care EMR," *J Am Med Inform Assoc*, 2003;10:616. Available at people.cs.uchicago.edu/~petemar1/56425/documents/616.pdf.
65 The American Academy of Family Physicians is trying to recruit other medical societies, including the American Medical Association, to help fund the development of a low-cost, open source EMR, and there are many other ongoing open source projects. See www.ama-assn.org/amednews/2003/02/17/bisb0217.htm.
66 CHI is an element of the Federal Health Architecture Program, which is in ONCHIT. It is part of the Office of Management and Budget's E-Government initiative. About 20 federal agencies, including the Department of Health and Human Services, the Department of Defense, and the Department of Veterans Affairs, are active in the CHI governance process. See www.os.dhhs.gov/healthit/chi.html.

Interoperability Consortium, as it is called, pledged support for nonproprietary (or open) standards that can serve as a common language.[67,68]

In another joint effort, HIMSS, the American Health Information Management Association, and the National Alliance for Health Information Technology last year formed the Certification Commission for Healthcare Information Technology, with the goal of forming a mechanism for the certification of health information technology products. This includes considering a minimum set of requirements for EMRs. The commission is also intended to address uncertainty about how well these products will work with one another and is scheduled to develop a standard for EMRs in ambulatory care settings by the summer of 2005.[69,70]

Are We There Yet?

There is a long way to go before a national network of EMR systems is in place. Although it is clear that pressure points for EMR adoption are growing within physician practices and in larger healthcare institutions, such as hospitals and provider systems, as well as within the federal government and through state initiatives, it is difficult to say when the United States will have a nationwide EMR system.

New data confirm that most practicing physicians are not using EMRs, even though more practices and systems are adopting them. EMR adoption has increased only slightly over the past two years, from 105,000 physicians in 2003 to 130,000 in April 2005.[71]

It may be only in retrospect that we will be able to discern just when the balance began to shift definitively toward the widespread adoption and use of this important element of healthcare technology.

67 Baker ML, "Health IT: Fears and Opportunities," *eWeek*, February 1, 2005, www.eweek.com/article2/0,1759,1758128,00.asp and www.ahqa.org/pub/connections/162_696_5100.cfm#tech.

68 In a report issued in response to ONCHIT's call for recommendations on how to develop a National Health Information Network, the consortium recommended that the federal government create a not-for-profit company called the National Health Standards Corporation that would include DHHS-appointed board members who would negotiate technology standards. The consortium issued a report saying that the government should provide seed funding and incentives to encourage physicians and hospitals to purchase the hardware and software needed to participate in the network and also recommended that the national health network not include a central database and that patients should have ownership of their health records and should be able to decide whether their information can be used in studies of drug and treatment effectiveness.

69 See www.ahanews.com/ahanews/jsp/display.jsp?dcrpath=AHANEWS/AHANewsNowArticle/data/ann_050418_certify&domain=AHANEWS. Also www.healthdatamanagement.com/html/PortalStory.cfm?type=trend&DID=11932. The Certification Commission for Healthcare Information Technology has released for public comment proposed requirements for certifying electronic health record products for the outpatient setting (www.cchit.org/publiccomment1.htm). The comments will be used to refine the requirements before the certification program is finalized and tested this summer.

70 In addition, ONCHIT is working with the Commission on Systemic Interoperability (of the National Library of Medicine), which is charged with addressing the development and implementation of healthcare information technology standards. It is due to release a report about its findings in the near future. See www.healthcareitnews.com/NewsArticleView.aspx?ContentID=2565 and www.nlm.nih.gov/csi/csi_home.html.

71 "New data from Manhattan Research confirms what national healthcare IT czar David J. Brailer, MD, and a host of other healthcare IT leaders have been asserting all along: The electronic medical record remains elusive for the majority of practicing physicians today. The conclusion is one of several the research firm published in 'Taking the Pulse v5.0: Physicians and Emerging Information Technologies,' an annual study focused on physicians' technology adoption.…EMR adoption has increased slightly over the past two years, from 105,000 physicians in 2003 to roughly 130,000 physicians today, according to the research." This study was conducted by Manhattan Research, which found that "…the electronic medical record remains elusive for the vast majority of practicing physicians today. However, the data reveal an emerging segment of physician pioneers (now exceeding 20% of the general physician population) utilizing an electronic medical record in their practice. Furthermore, these EMR pioneers are up to 5 times more likely to utilize complementary technologies such as electronic prescribing, online consultations, and mobile computing devices." See www.healthcareitnews.com/NewsArticleView.aspx?ContentID=2818 and www.manhattanresearch.com/Taking%20the%20Pulse%20v5%20(051205).pdf.

V. Challenges of Adapting the EMR as a Research Tool

In attempting to arrive at the truth, I have applied everywhere for information, but in scarcely an instance have I been able to obtain hospital records fit for any purpose of comparison. **Florence Nightingale (1873 essay Notes on a Hospital)**

If Florence Nightingale were alive today, she might be encouraged by the move toward EMRs. But she might also be wise enough to realize that implementing the EMR will not automatically improve data quality—data still have to be analyzed and processed to provide relevant information, and information has to be converted into knowledge, which must then be appropriately managed.

Even if all health providers and systems adopt EMRs, there is no guarantee that these systems would be useful for research. EMR systems must be built with research in mind. In general, however, the system design goals or "systems thinking" of the administrative/information technologist is not consistent with that of a research or public health function.

All of the problems that plague widespread adoption of EMRs for patient care also apply to their use in research. A survey of 28 members of the Academic Health Centers' Clinical Research Forum was conducted to determine the current state of information technology support for clinical research.[72] More than half of the respondents said that their institution has no strategic vision for information technology and clinical research. While modest improvements have been made in electronic data capture for clinical research, major problems were cited, including organizational governance structures, the lack of a standard vocabulary and coding schemes, and fragmented information technology services and budgets.

Several individuals interviewed by the authors of this report commented that although most are aware of the need for institutions to build information technology for clinical research, clinical researchers often do not have the time or authority to help implement new technical solutions. This results in limited involvement by clinical researchers in setting institutional strategies and priorities or purchasing and building new systems.

The famous computer axiom, "garbage in, garbage out" (or GIGO), is particularly relevant when considering the use of clinical practice data for research purposes. To serve research needs, EMR systems will have to meet different and somewhat higher standards. They must provide:

- reliable and complete data;
- the ability to search across records;
- secure accessibility;
- common informatics standards and interoperable interfaces;
- user-friendly informatics tools;
- informatics tools that merge patient care data with clinical research data, while maintaining data security and privacy;
- standard definitions of diseases, conditions, and adverse events; and
- the use of standard minimal (core) data elements across networks, diseases, and conditions.

72 Survey results available at www.ahcforum.org/presentations/2GlaserSurveyFinal(AHC).ppt.

In addition, EMR databases must overcome issues relating to:

- differences in network and institutional governance;
- study management;
- investigator interests;
- disease definitions;
- reporting procedures;
- core patient data; and
- data and specimen sharing policies.

Ideally, EMRs could provide the technical capacity and infrastructure on which longitudinal medical records—that is, health data on individuals over their lifespan—can be built. These could then be integrated across sites of care and tapped by health services researchers, clinical researchers, and those involved in quality improvement efforts. Such records could then be shared if they adhere to certain standards—for example, standard vocabularies such as LOINC and SNOMED, standard messaging formats such as HL7, and standard formats for image exchange, such as DICOM (see Appendix C).

Several systemic problems must first be addressed, however, if EMRs are to be useful for research.

The Art and Practice of Medicine

There is no one way to practice medicine. Clinicians are trained at hundreds of schools of medicine around the world. They learn to observe and record data in numerous ways, resulting in differences in language and style. One radiologist might observe that "lung fields are unremarkable," and another might record "lack of infiltrate." Both observations refer to a normal radiological reading but suggest that there might be an untold story behind the initial request for the chest X-ray. Did the first doctor anticipate a normal reading and the second suspect an abnormal result based on the symptoms of the patient?

Standardization of clinical data is also difficult in practice because not all procedures are performed in the same way. For example, measuring blood pressure when the patient is sitting will give a different result than measuring it when the patient is standing. Even seemingly simple measurements such as height or weight are likely to differ among practices. And demographic information, such as race, is even more difficult to document. Several studies have highlighted that there is a normal level of disagreement among physicians that can be expected for the clinical interpretation of reports, such as radiography reports.[73]

Variation in clinical care delivery and in patient outcomes can be extensive and is often the focus of health services research. Numerous studies have shown, for example, as much as a seven-fold difference in test ordering practices among physicians or significant differences across regions for hospitalization rates of patients with the same diagnosis. In addition, when physicians select patients for diagnostic procedures and treatments, they introduce bias that can grossly affect studies of the natural history of disease and its treatment.

The adoption of standards such as HL7, LOINC, and SNOMED will be very helpful in leveling the playing field. However, these coding systems are highly variable and individualized, and some, which are proprietary, require the user to pay significant fees for their use,[74] which will skew adoption. In any event, physician variability is not something that can be eliminated from the healthcare system; nor would we want such an impersonal outcome.

A researcher works with data, while the healthcare professional's first priority is the person. Clinicians record only what is necessary or "pertinent normal," and the reality is that we cannot ask doctors to record more information in the limited time they have available for each visit.

Thus, it is not likely that a patient care record can always capture the refined, comparable, and consistent data needed by researchers.

From an informatics perspective, the computer cannot (currently) replace an astute clinician's observations and hypotheses. One investigator noted that, "We can't write a program to duplicate a human's 'correlations of interest' or observations." Despite some automated queries, data mining, and knowledge discovery strategies, more work is needed in developing exploratory data analysis.

The practice of medicine is an art, not a trade; a calling, not a business; a calling in which your heart will be exercised equally with your head.

Clinician and Medical Educator William Osler

73 Hripcsak G et al., "Unlocking Clinical Data from Narrative Reports: A Study of Natural Language Processing," *Ann Intern Med*, 1995;122(9):681-688.

74 AAMC, *Information Technology Enabling Clinical Research. Findings and Recommendations from a Conference Sponsored by the Association of American Medical Colleges with Funding from the National Science Foundation*, 2003, AAMC: Washington, DC:73, www.aamc.org/members/gir/clincalresearchreport.pdf.

Nonetheless, to be accurate, automated systems require coded data from a well-defined, finite vocabulary, and the relations among the concepts must be expressed in an unambiguous and formal structure.[75] Caution is required, because research or care decisions made based on inaccurate clinical data extracted from patient records can potentially affect large numbers of patients.

Reliability and Completeness of the Record

It is clear that relying on disconnected and incomplete clinical records will not be sufficient for clinical research. A 2005 study published in the *Journal of the American Medical Association* found that clinical information is missing in the records of almost 14 percent of visits to primary care physicians.[76] Missing information included laboratory results, letters, radiology results, medical history, results of physical examinations, and medications.

Limited evidence suggests that when physicians use computer- versus paper-based records, they are more likely to complete the necessary documentation.[77] However, this does not necessarily translate into accuracy. In fact, a 2004 study of primary care patients found a high rate of inaccuracy in computerized medication histories. There was complete agreement between the computer medication list and what the patient was actually taking in only 5.3 percent of the patient records studied.[78]

According to Stephen Rosenfeld, Chief of the Department of Clinical Research Informatics at NIH, however, statistical methods can be developed to establish a minimum acceptable set of data to be gathered at baseline to ensure that the study has the necessary power to be meaningful. In other words, programs can be written to account and adjust for missing data.

Researchers and statisticians are developing methods to account for missing data. Objective data can often serve as a proxy for missing subjective impressions—patients taking insulin, for example, can be reliably labeled as a diabetic even if that diagnostic information is missing.

Limits of Administrative and Claims Databases

Most of the EMR software systems in use today have an administrative/transactions orientation, and if they are linked as a database it is frequently for the purposes of billing, claims, scheduling, outcomes assessment, and resource management. This does not in any way minimize the importance of the EMR for patient-centered care—its primary purpose. Rather, it suggests that these systems have been designed to support clinical workflow and are not easily adapted for research use. In fact, some of the commercial system vendors that have developed the legacy systems or subsequent enhancements have relied on business models that intentionally reduce the flexibility and accessibility of data for re-use.[79]

In addition to the inflexibility of these systems, they do not always lend themselves to research use because of their lack of sensitivity and completeness. Although claims databases contain diagnostic information obtained from physicians or chart abstracters,[80] this information is often secondary; that is, it represents an interpretation of the data contained within the patient record. For example, abstracters may not identify diabetes as a problem or they may not code it at all if another diagnosis—for example, back pain—was the primary focus of the patient visit. Thus, traditional diagnostic codes can be unreliable for research. The clinical events or coexisting conditions must be noted by the clinician, who must then record them properly, and the person abstracting the data must identify the diagnosis and code it appropriately.

Insurance claims databases also lack important diagnostic and prognostic information when compared to clinical databases. For example, in a study of nearly 13,000 patients hospitalized for cardiac catheterization for suspected ischemic heart disease, claims databases failed to identify more than one half of the patients with prognostically important conditions such as congestive heart failure, peripheral vascular disease, tobacco use, and angina, among others.[81] A more recent study found that the correct primary diagnosis

75 Hripcsak G et al., "Unlocking Clinical Data from Narrative Reports: A Study of Natural Language Processing," *Ann Intern Med*, 1995;122(9):681-688.

76 Smith PC et al., "Missing Clinical Information During Primary Care Visits," *JAMA*, 2005;293(5):565-571.

77 Tang PC, LaRosa MP, Gorden SM, "Use of Computer-Based Records, Completeness of Documentation, and Appropriateness of Documented Clinical Decisions," *J Am Med* Inform Assoc, 1999;6(3):245-251; Hippisley-Cox J et al., "The Electronic Patient Record in Primary Care—Regression or Progression? A Cross Sectional Study, *BMJ*, 2003;326(7404):1439-1443.

78 Kaboli PJ et al., "Assessing the Accuracy of Computerized Medication Histories," *Am J Manag Care*, 2004;10(11 Pt 2):872-877.

79 Association of American Medical Colleges (AAMC), *Information Technology Enabling Clinical Research. Findings and Recommendations from a Conference Sponsored by the Association of American Medical Colleges with Funding from the National Science Foundation*, 2003, AAMC: Washington, DC:73.

80 The Medicaid Management Information System and the Medicare database are examples of databases constructed from hospital case abstracts.

81 Jollis JG et al., "Discordance of Databases Designed for Claims Payment Versus Clinical Information Systems. Implications for Outcomes Research," *Ann Intern Med*, 1993;119(8):844-850.

was recorded in only 57 percent of cases reviewed; the accuracy of the secondary diagnosis was worse, at 27 percent.[82]

Typical administrative databases built off of EMRs can constrain the richness of clinical observations. For example, one can code only a limited number of diagnoses, and the goal is to maximize payment, not to achieve perfect clinical accuracy. Medicare uses Diagnosis Related Groups, or DRGs, to assign a diagnosis at the point of discharge. They are also used for payment decisions. This approach has led to large variation among patients within particular DRGs. It also has produced "DRG drift," in which better paying diagnoses are selected as primary over lesser paying ones when patients have more than one active condition.[83]

An additional complication arises with the use of Current Procedural Terminology (CPT) codes, which are published by the American Medical Association. The guidelines for their use suggest that when a minor procedure is performed as part of a more substantial one, it should be bundled into the larger procedure rather than coded as a separate procedure. An investigation by the Office of the Inspector General at HHS found that in the late 1980s, up to 13 percent of claims for any given procedure were being miscoded.[84] Reliance on DRG or CPT codes is no way to conduct research, even though they are the predominant coding schemes in several EMR systems.

Systems that can automate the coding of clinical reports will be a better source of information than those that provide financial discharge data. This distinction is important, given the general assumption that financial discharge coding can support clinical research goals, especially the screening of records to find potential research subjects.

The Problem of Unstructured Text in a Medical Record

Medicine is an observational science. Clinicians observe and record, and much of the patient record consists of physicians' notes and comments. Yet the richness of medical concepts and clinical observations creates a challenge to standardizing medical records for the purposes of comparison and analysis. Although laboratory results are routinely available in electronic form, much of the most important medical information does not easily translate in automated systems. And even though human coders can be trained to read and manually structure narrative reports, it is time-consuming and expensive and is often justifiable within an institution only when being done for billing purposes. In addition, manual coding systems do not match the speed and simplicity that can be attained by simply dictating narrative reports.

Natural language processing (NLP) is an exciting new area that has the potential to create huge and clinically rich databases from narrative reports (see Box F). Perhaps the most extensive progress in this area has been in the field of chest radiographic reports, because they are fairly simple to read and interpret, but this approach has also been tested on more complex narrative reports such as CT and MRI imaging of the head.[85] At least two independent groups have demonstrated that NLP can be as accurate as expert human coders for coding radiographic reports, as well as more accurate than simple text-based methods, such as searching for relevant phrases in the reports.[86]

Investigators in one study demonstrated the effective use of NLP processing to improve clinical care by improving respiratory isolation for tuberculosis.[87] The potential of NLP to facilitate clinical research also has been demonstrated in an analysis of a stroke database of 471 patient records.[88]

82 Peabody JW et al., "Assessing the Accuracy of Administrative Data in Health Information Systems," *Med Care*, 2004;42(11):1066-1072.
83 Lorence DP, Ibrahim IA, "Benchmarking Variation in Coding Accuracy Across the United States, *J Health Care Finance*, 2003;29(4):29-42; Tierney WM, McDonald CJ, "Practice Databases and Their Uses in Clinical Research, *Stat Med*, 1991;10(4):541-557.
84 Kesselheim AS, Brennan TA, "Overbilling vs. Downcoding—The Battle Between Physicians and Insurers," *N Engl J Med*, 2005;352(9):855-857.
85 Hripcsak, G., et al., "Use of Natural Language Processing to Translate Clinical Information from a Database of 889,921 Chest Radiographic Reports. *Radiology*, 2002. 224(1): p. 157-163.
86 Hripcsak G et al., "Unlocking Clinical Data from Narrative Reports: A Study of Natural Language Processing, *Ann Intern Med*, 1995;122(9):681-688; Hripcsak G, Kuperman GJ, Friedman C, "Extracting Findings from Narrative Reports: Software Transferability and Sources of Physician Disagreement," *Methods Inf Med*, 1998;37(1):1-7; Hripcsak G et al., "Use of Natural Language Processing to Translate Clinical Information from a Database of 889,921 Chest Radiographic Reports," *Radiology*, 2002;224(1):157-163; Fiszman M et al., "Automatic Detection of Acute Bacterial Pneumonia from Chest X-Ray Reports," *J Am Med Inform Assoc*, 2000:7(6):593-604.
87 Knirsch CA et al., "Respiratory Isolation of Tuberculosis Patients Using Clinical Guidelines and an Automated Clinical Decision Support System," *Infect Control Hosp Epidemiol*, 1998;19(2):94-100.
88 Elkins JS et al., "Coding Neuroradiology Reports for the Northern Manhattan Stroke Study: A Comparison of Natural Language Processing and Manual Review," *Comput Biomed Res*, 2000;33(1):1-10.

Alternatives to NLP have also been assessed as a means to analyze unstructured and uncoded text. In some cases, a simple text-based search engine can detect relevant reports in a large database. For example, screening medical discharge summaries could provide information about adverse events. One group of investigators developed a computerized screening tool that searched free-text discharge summaries for trigger words representing adverse events.[89] They found the positive predictive value of such tools to be 52 percent, indicating that although free text searching is feasible, it has poor specificity. Nonetheless, it has been demonstrated that NLP can achieve higher accuracy than such search engines.[90] The full potential of NLP will not be realized until it can be extended to very complex narrative reports, such as admission notes and discharge summaries.

In its anticipated form, NLP could put the information in millions of clinical reports at the fingertips of researchers and clinicians.

BOX F What Is NLP?

NLP, or natural language processing, is the name for a subfield of artificial intelligence studies in computer science. It deals with the parsing, processing, and analysis of human language to map it into a machine-usable format (for a database, for writing program code, or for issuing commands to control software or systems) or by extension to translate between one language (set of jargon, grammar, and vocabulary) and another. This general idea, developed more fully and specifically tailored to the medical field, could be an important key in making cross-EMR research tools truly functional. Because each EMR almost certainly will have at least slightly different terminology and different syntax for data about patients, cases, treatments, and outcomes, a process will be needed to standardize all of the variables that may arise when someone searches a range of data sources. That process will involve something like NLP.

Many companies, such as IBM, are devoting a lot of research time and money to NLP research and development, and IBM already has developed a medical application of this technology. A TAKMI (Text Analysis and Knowledge Mining) system (called MedTAKMI) is being tested for analyzing medical publications. Although still in early development/ preproduction status, it is apparently sufficiently functional that it is capable of mining the entire MEDLINE database of 11 million biomedical journal abstracts. However, when applied to medical records, the issues of access, authentication, security, and privacy all would need to be addressed in designing any additional interface, which would then need to be coded (a matter of hundreds, probably thousands, of hours of work).

In addition, several efforts are under way at academic medical centers. An apparently more research-oriented, noncommercial project is unfolding at Columbia University, where MedLEE (Medical Language Extraction and Encoding System) is in development. MedLEE will provide researchers with predesigned reports they can run against a database, eventually with the ability to write free-form queries with different parameters. In addition to Columbia University's extensive work, particularly in radiology, Stanford University is developing a program to convert true text into preferred terminology. Others are watching and waiting. John Gallin, Director of the Clinical Center at NIH, says that such software programs are sorely needed, and once proven will be widely adopted.

Other commercial NLP products include the following:

Lifecode NLP (A-Life Medical)
This is mostly patient/provider oriented, for automated analysis of records in a clinical setting; however, the underlying technology could be used as a base for a statistical research-oriented product.

LinKSuite (Language & Computing)
The main product relevant to database searching and linking is LinKSuite. Although not designed or built to link multiple EMRs together, it appears to be intended for use by a single institution, such as a campus-wide system of multiple departments or practices. The system is based on collecting data in a central database and then using a sophisticated NLP program to conduct queries directed to the database.

89 Murff HJ et al., "Electronically Screening Discharge Summaries for Adverse Medical Events," *J Am Med Inform Assoc*, 2003;10(4):339-350.
90 Hripcsak G et al., "Use of Natural Language Processing to Translate Clinical Information from a Database of 889,921 Chest Radiographic Reports," *Radiology*, 2002;224(1):157-163.

Integrating Practice Databases for Data Mining

Impressive examples of EMR systems are in place both in U.S. hospitals and in some ambulatory practices. However, Henry Lowe at Stanford University estimates that less than 20 percent of large institutions have an EMR system in place. For example, for many years several hundred ambulatory care sites have used COSTAR, a public domain computer-based ambulatory medical record system developed at Massachusetts General Hospital. In COSTAR, the medical data for a patient visit are transcribed into the computer system by clerical personnel.

Other examples of computer-based systems include the electronic record developed at the Regenstrief Institute at Indiana University, where a clinician can view a patient's problem list and laboratory data interactively as flowsheets, allowing easier detection of trends. An ambulatory computer-based record at Boston's Brigham and Women's Hospital also provides a summary screen displaying a "patient-at-a-glance" with a problem list, allergies, and medications. In these systems, like many similar systems, the patient information is accessed either through direct inquiry at a computer terminal or through computer-generated summaries and reports.

EMR systems have been shown to enhance the quality of care, reduce costs, and improve the management of healthcare.[91] In addition to routine billing and administrative tasks, some of these databases have been used to investigate clinical epidemiology, conduct risk assessments, carry out post-marketing surveillance of drugs, study practice variation and resource uses, perform quality assurance, and implement decision analysis. These practice databases can also be used to identify potential subjects for clinical studies (see Section III for further discussion of these activities at specific institutions).

Will all of these efforts be creating new silos of information that will mount technical and cultural barriers to mining data across institutions? In theory, all of the systems being developed should be able to communicate with one another, but that will depend on who adopts what system. A critical mass of multispecialty group practice users are choosing the same software vendor, including Kaiser Permanente, Cleveland Clinic, University of California at Davis, and Palo Alto Medical Foundation (Sutter Health), a development that may lead to increased opportunities for interoperability among care systems. Under the auspices of the Council on Accountable Physician Practices, some of these group practices are beginning to meet with each other to standardize data flow and share learning.[92]

It is technically possible to build software that communicates between different databases so that they can translate records from one to another or so that a third program can query both (or all) databases for specific information. However, this is a very complex undertaking. The programmer of the searching or linking software must have complete information about exactly how each database is constructed, what communications protocols it uses, what operating system it is housed on, and more. In addition, once the basic ability to communicate information between or across databases is established, the programmers need to work with the database designers and users to build a translation matrix for such things as database field names, terminology used within the database, numeric measures used, and all of the jargon specific to the field concerned with each database. For example, two systems may have different names for a field that lists a patient's primary chronic health condition and within that field may use different terms or abbreviations for the same condition. For fields such as medication, the systems may again use different terms, and they also may have different systems for coding data such as dosages, times for taking medicines, durations of treatments, and more. The development of standards will be critical.

Much is known, but unfortunately in different heads. **Scientist Werner Kollath**

Additionally, to protect privacy and confidentiality, patient care records must be abstracted, encrypted, and/or de-identified before being used for research. In many cases, this requires that institutions providing care and conducting research run two separate systems —a "transactional" system for care and a "warehouse" system for data queries. Several large research institutions, for example, Stanford University and the Dana Farber Cancer Institute, are developing systems to move data from real-time clinical records to research repositories. This goal is not easily accomplished, because most clinical EMR systems are designed to support clinical workflow, not research.

91 Asch SM et al., "Comparison of Quality of Care for Patients in the Veterans Health Administration and Patients in a National Sample," *Ann Intern Med*, 2004;141(12):938-945; Owen RR et al., "Use of Electronic Medical Record Data for Quality Improvement in Schizophrenia Treatment," *J Am Med Inform Assoc*, 2004;11(5):351-357.

92 Halvorson GC, "Reengineering Care with KP HealthConnect," *The Permanente Journal*, 2004;8(4):28-31.

To facilitate data mining of EMR databases by investigators, all the systems to be searched need to be accessible somehow by the researcher (or, more specifically, by the software the researcher is using).

This can be accomplished using:

1. HTTP (Web-type) connections;
2. more specific database connection tools (generically called Open Database Connectivity software); or
3. a yet-to-be-developed standard.

The systems also need to be able to communicate with each other or the researcher on a physical level. They could be Internet connected, or there could be dedicated private links set up between the research program and each target database.

Second, all of the translation issues between different systems and formats need to be addressed. This would require software to make all of the translations and more. Every database would need to be searched, and each search's results would need to be filtered to put everything into a common set of terms and formats.

Third, the issue of patient consent would need to be addressed. Some people will be willing to have their medical data used for research (see discussion below); however, some will not. This would probably have to be addressed at the time of collection of the data, perhaps with each EMR having two subsets of data. One would be open to searching for data and one would not, or perhaps each set of records would have a flag that indicates "yes, you can view this data" or "no, this data is to be kept hidden."

Fourth, there is the issue of anonymity—some mechanism would need to be developed and enforced that would anonymize the data to be searched appropriately. There are several levels of anonymity, so "how anonymous" to make each record would need to be factored in. This might be dealt with in the design of a specific EMR's database, but because some might store their data with more or less personally identifying information, the research/data mining software would need to be built so that it was aware somehow of what it was getting and could strip personal information out of its input stream as appropriate.

These are obviously complex and challenging problems to be addressed if EMR systems are to become useful research resources. While technically possible, this task will be difficult to achieve in the absence of a central authority providing guidance and a clear, detailed set of standards and instructions for the designers and users of EMRs, as well as for the developers and users of searching and interconnecting tools.

Research Regulations

Common Rule

The human research enterprise is highly regulated, and medical records research is no exception. The major ethical concerns in research with human subjects focus on the protection of privacy and confidentiality and the minimization of risk. The system by which these protections are enforced is embodied in the current Federal Policy for the Protection of Human Subjects in Research (referred to as the "Common Rule" or HHS regulations at 45 CFR 46). The Common Rule is based on sound and universally accepted ethical principles developed over the past 40 years. As such, it serves as a useful departure point for any system of protection of research subjects, regardless of the source of the research support (public versus private).

Similar regulations adopted by the Food and Drug Administration (FDA) apply to human subjects research conducted to develop products currently regulated by FDA (21 CFR Parts 50 and 56). Research sponsors, investigators, and states can also impose more stringent requirements if desired or necessary.

Thus, any large database of identifiable personal health information will be subject to the Common Rule, FDA requirements, or both. Recent guidance issued by the federal Office for Human Research Protections states that entities are considered engaged in human subjects research, and therefore must meet the regulatory requirements, even if they are only in possession of personal health information that is individually identifiable (either directly or indirectly through codes).

According to the Common Rule and general practice, the twin protections of informed consent and independent review of research by an IRB provide the foundation for an ethical approach to human subjects research. Provided that adequate protections exist (which usually, but not always, include informed consent), medical information gathering could include ongoing collection of medical records data and even requests for individuals to undergo tests to provide additional research information. In some cases, it will even be acceptable for investigators to convey information about research results to the persons whose data have been studied. Where identifying information exists, a well-developed system of protections must be implemented to ensure that risks to subjects are minimized and that the interests of data sources are protected.

The review of medical records for research purposes is exempt under the Common Rule if the information is recorded by the investigator in such a way that it does not identify the patient. However, institutional procedures and requirements related to records research vary; some institutions may require IRB review for such research. Much records research may qualify for expedited IRB review under the Common Rule. Thus, research involving review of medical record information in which the identity of the patient is known requires IRB review. The IRB then makes a determination based on a risk assessment of whether the consent of the individual must be obtained or can be waived.

Health Insurance Portability and Accountability Act (HIPAA)

Research institutions have been implementing the human subjects regulations for more than a decade and are familiar with the requirements. However, a new set of regulations, embodied in HIPAA, has imposed a new set of requirements for research using personal health information.

The HIPAA Privacy Rule governs the protection of individually identifiable health information and was enacted to increase the privacy protection of health information with individual identifiers and to regulate known and unanticipated risks to privacy that may accompany the use and disclosure of such identified personal health information. It covers individually identifiable health information that is held or maintained by "covered entities" (health plans, healthcare clearinghouses, or healthcare providers who transmit health information for certain transactions) or by business associates acting for a covered entity.

The Privacy Rule generally requires authorization from individuals to use their protected health information in research, unless an exception applies. This authorization is distinct from informed consent, which is a separate process required under the Common Rule.

Many institutions and investigators say that determining compliance with HIPAA remains confusing. Interviews with several clinical investigators revealed rising concern about the effect of HIPAA on research. Most claim that the law is slowing clinical research because of the cost and time required to comply with HIPAA and because of the tendency of the provider community to misinterpret its implications for research.

Edward Benz, President of the Dana-Farber Cancer Institute, says that HIPAA has made clinical research more expensive because it has lengthened the time it takes to start a study. Bernard Lo, Professor of Medicine and Director of the Program in Medical Ethics at the University of California, San Francisco, says that until HIPAA issues are resolved for the research community, the promise of EMRs as a research resource could fall flat.

According to a survey by the healthcare information management firm Phoenix Health Systems, 25 percent of 318 organizations surveyed still had not met all the HIPAA requirements, nearly two years after the deadline.[93] The primary reason for noncompliance was achieving successful integration of new systems, policies, and procedures across the enterprise. The ambiguity of the rule was the second most cited reason.

Moving Forward

EMR systems have the capability to serve as a broadly enabling research infrastructure that facilitates and promotes the sharing and reuse of data from the patient care process and that channels the results of clinical research back into the hands of patients and practitioners, where it can do the most good.

The greatest challenge to using the EMR for research is the reliability and validity of the data in the record. The bottom line is that data are as reliable as the patient gives and the user enters. Although clinical data generally are valid, there may be mistakes or omissions. In addition, although billing codes are considered part of the record, they are the least useful and reliable data elements for researchers and therefore almost meaningless for most clinical research.

At some point soon, a critical mass may be reached in EMR adoption that will help accelerate substantially greater progress in standardization. This must occur in tandem with efforts to integrate multiple databases for data mining. Standards for security and confidentiality also are needed, as is the consistent use of messaging standards.

93 See www.hipaadvisory.com/action/surveynew/results/winter2005.htm.

VI. Summary

In this paper we have outlined the various challenges faced by healthcare systems as they migrate toward EMR systems and the obstacles that must be overcome if the EMR is to meet its potential as a research resource, and we have described some of the innovative programs under way to make use of this new capability (see Box G).

The primary purpose of EMR systems—improved healthcare—will be well-served as more providers come online. Ideally, patients will benefit from a healthcare system that is integrated across time, professionals, and institutions. The EMR has the potential to recognize the interdependence of the many working parts of the healthcare system to effectively manage the entire continuum of care. EMR systems, able to communicate across providers, will allow patient information to flow across all components of care, across geographic sites, and across discrete patient care incidents.

The value of such longitudinal records to improved health is obvious. However, it is shortsighted if we do not also consider the potential vast benefits such systems could provide clinical researchers.

The application of information technology to patient records offers the promise of new knowledge that can be obtained only by integrating and analyzing data extracted from hundreds if not thousands of patient records, including clinical information, medical images, environmental profiles, and genetic analyses, combined with new findings from molecular and genomics research. As institutions struggle with the adoption and implementation of EMR systems, it is crucial that they consider the needs of and seek the advice of the research community.

Importantly, improvements made in EMR systems in response to research needs will ultimately serve clinical care needs as well. For example, at the Mayo Clinic researchers are trying to address problems that they encounter because records are not always consistent or comparable. In trying to achieve consistency and standardization, patient record systems will not only become more useful for research but also will contribute to improved quality of patient care.

BOX G

EMRs and Research: Challenges and Solutions

Challenges to Widespread EMR System Adoption
Cost
Infrastructure requirements
Acceptance by and training of healthcare providers
Interoperability of systems (hardware, software)
Standard vocabularies and presentation formats
Security and privacy
Ownership issues
Organizational and cultural factors

Challenges to Research Uses of EMRs
Reliability and completeness of the record
Limits of legacy databases (administrative and transactional)
Variability in medical practice
Pervasiveness of unstructured text
Lack of specificity of patient data
Ability to look across many records and many databases
Privacy and human subjects protections regulations

Emerging Solutions
Integration of practice databases for data mining
More sophisticated abstraction and encryption systems
Development of database connection tools
Creation of translational systems
Online informed consent procedures
Evolving data mining and pattern recognition systems
Interactive patient query programs
Creation of patient databases/warehouses/registries
Directories of clinical databases

Likewise, the development of customized algorithms and pattern recognition systems will aid researchers while simultaneously providing physicians with smart clinical decision-support tools.

Other models, such as Geisinger Health System, are testing the power of information technology to improve patient care through the use of online interactive self-assessment. It is conceivable that such an approach could be modified and easily adapted for research purposes.

Still other systems, such as Kaiser, are exploring ways in which to use transactional systems for patient care in combination with data warehouses to run research queries. Such data warehouses can be used to plan studies, conduct post-marketing surveillance, or test exploratory data analyses, an approach that goes beyond simply relying on human intelligence to test theories.

Other large federally funded EMR systems, such as those operated by IHS and VHA, have the potential to provide vast amounts of patient data for clinical research. Yet their use for this purpose remains limited.

A promising variation on the theme of the EMR as a research tool is the development of clinical database directories such as DoCDat and patient data registries, such as those created by Partners HealthCare and several other large providers. These systems gather data from numerous hospital and provider legacy systems for storage in one place. Exciting efforts are under way to accurately store images as well as unstructured data.

The clinical research community sees enormous potential in the ability of researchers to access and analyze the clinical information contained in millions of medical and personal health records. With appropriate privacy and human subjects protection safeguards in place, this capability could speed the discovery of new therapies beyond anything imaginable today.

There is a long way to go before a national network of EMR systems is in place. Although it is clear that pressure to adopt EMRs is growing within physician practices and in larger healthcare institutions, as well as within the federal government and through state initiatives, many challenges remain. However, these challenges can be met, given the will and the resources. The path to an EMR system that also serves the needs of researchers is a long one, but it is one that must be mapped so that no important opportunity is missed.

VII. Appendices: Appendix A

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Appendix B

Acronyms

AHRQ Agency for Healthcare Research and Quality

ARAMIS Arthritis, Rheumatism, and Aging Medical Information System

CCHIT Certification Commission for Healthcare Information Technology

CDS clinical decision support

CHI Consolidated Health Informatics initiative

CHORUS Collaborations in HIV Outcomes Research/United States

CMS Centers for Medicare and Medicaid Services

CPOE Computerized Provider Order Entry

CPT Current Procedural Terminology

COSTAR Computer Stored Ambulatory Record

DBMS database management system

DICOM Digital Imaging and Communications in Medicine

DOD Department of Defense

DRGs Diagnosis Related Groups

DSS decision support system

EDI electronic data interchange

EHR electronic health record

EMR electronic medical record

FDA Food and Drug Administration

FHA Federal Health Architecture

FOIA Freedom of Information Act

GPRD General Practice Research Database

HHS Department of Health and Human Services

HIMSS Healthcare Information and Management Systems Society

HIPAA Health Insurance Portability and Accountability Act of 1996

HIT health information technology

HL7 Health Level 7

IHS Indian Health Service

IHS EHR Indian Health Service Electronic Health Record

IOM Institute of Medicine

IRB Institutional Review Board

LLDB large-linked database

LOINC Logical Observation Identifiers, Names, and Codes

MedLEE Medical Language Extraction and Encoding System

NDW National Data Warehouse

NECTAR National Electronic Clinical Trials and Research

NHII National Health Information Infrastructure

NHIN National Health Information Network

NIH National Institutes of Health

NLP natural language processing

NSAIDS nonsteroidal anti-inflammatory drugs

ONCHIT Office of the National Coordinator for Health Information Technology

PCC Patient Care Component

PHR personal health record

RHIO Regional Health Information Organization

RMRS Regenstrief Medical Records System

RPDR Partners Healthcare Research Patient Data Registry

RPMS Resource and Patient Management System

SEER Surveillance, Epidemiology, and End Results Program

SNOMED-CT Systematized Nomenclature of Medicine-Clinical Terms

TAKMI Text Analysis and Knowledge Mining

VA Department of Veterans Affairs

VHA Veterans Health Administration

VHA's EHR Veterans Health Administration's Electronic Healthcare Record

VistA Veterans Health Information Systems and Technology Architecture

VSD Vaccine Safety Datalink

Appendix C

Glossary of Terms

Advanced Encryption Standard (AES). The new standard cryptographic algorithm for use by U.S. government organizations. Used to protect sensitive (unclassified) information. Also known as Rijndael, it is expected to be used across the world and was adopted by the National Institute of Standards and Technology in November 2001 after a five-year standardization process.

Advanced Technology Program (ATP). Part of the National Institute of Standards and Technology, ATP, through partnerships with the private sector, is working to accelerate the development of innovative technologies that may result in significant commercial payoffs and widespread benefits.

Agency for Healthcare Research and Quality (AHRQ). Part of HHS, AHRQ has launched some pilot projects to study the development and adoption of health information technology. In September 2004, AHRQ awarded $139 million in contracts and grants to promote the use of health information technology.

American Academy of Family Physicians (AAFP). A national association of family doctors, with more than 94,000 members in 50 states, the District of Columbia, Puerto Rico, the Virgin Islands, and Guam.

American Academy of Family Physicians Center for Health Information Technology (CHIT). Developed to promote and facilitate the adoption and optimal use of health information technology by AAFP members and other office-based clinicians. CHIT is focused on technical expertise, advocacy, research, and member services associated with medical office automation and computerization.

American Health Information Management Association (AHIMA). A national association for health information management professionals. AHIMA works to improve the quality of medical records and provides leadership in advocacy, education, certification, and lifelong learning.

American Medical Informatics Association (AMIA). A nonprofit 501(c)(3) membership organization of individuals, institutions, and corporations with the goal of developing and using information technologies to improve healthcare.

American National Standards Institute (ANSI). A voluntary organization of more than 1,300 members that creates standards for the computer industry, including standards for programming languages and in technical areas ranging from electrical specifications to communications protocols.

American Society for Testing and Materials International (ASTM). A component of the American National Standards Institute, with an E31 subcommittee for general healthcare informatics. ASTM develops voluntary consensus standards, related technical information, and services related to the architecture, content, storage, security, confidentiality, functionality, and communication of information used within healthcare. It is one of the largest voluntary standards development organizations in the world.

American Society for Testing and Materials International Committee E31 on Healthcare Informatics. Develops standards related to the architecture, content, storage, security, confidentiality, functionality, and communication of information used within healthcare and healthcare decisionmaking.

Archiving. A method of transferring information created during operations into a more permanent form, with a variety of different systems available.

Association of American Medical Colleges (AAMC). A nonprofit association of medical schools, teaching hospitals, and academic societies that assists academic medicine's institutions, organizations, and individuals in medical education, medical research, and patient care.

Bioinformatics. The collection, organization, and analysis of large amounts of biological data, using computers and databases. Bioinformatics has expanded from a focus on the analysis of the sequences of genes and their products to include the management, processing, analysis, and visualization of large quantities of data from genomics, proteomics, drug screening, and medicinal chemistry. It also includes the integration and mining of the databases of information that are created from these disciplines.

Biometric authentication. Includes methods for securing electronic information for a specific user by determining an individual's physical features through an authentication inquiry and comparing this information with stored biometric reference data.

Centers for Medicare and Medicaid Services (CMS). The Department of Health and Human Services agency responsible for Medicare and parts of Medicaid. CMS is also responsible for oversight of HIPAA administrative simplification transaction and code sets, health identifiers, and security standards.

Certification Commission for Healthcare Information Technology (CCHIT). Created by HIMSS, AHIMA and NAHIT, is developing a process for certifying EHR products for physician offices. It will also consider product interoperability on a local and national scale, the use of incentives, and options for increasing the adoption of interoperable health information technology in this country. A basic certification process is expected by the summer of 2005.

Classification. Systematic representation of terms and concepts and the relationship between them. ***Clinical classifications*** are useful in the areas of clinical decisionmaking and research. They usually aim to be accurate and complete and have unambiguous expressions.

Clinical data repository (CDR). A repository of clinical information for use by clinicians and others in support of patient care. Data are organized in a format that supports the clinical decisionmaking process needed for patient care no matter where the patient information might be physically located.

Clinical decision support (CDS). Applications that integrate a medical knowledge base, patient data, and an inference engine to generate case-specific advice.

Clinical information system. A system relating exclusively to the information regarding the care of a patient, rather than administrative data.

Codes. Numeric or alphanumeric abbreviations that can expand into some meaning. In medical systems, the unique numerical identifier associated with a medical concept, which may be associated with a variety of terms, all with the same meaning.

College of Healthcare Information Management Executives (CHIME). Serves the professional needs of healthcare chief information officers and advances the strategic application of information technology in innovative ways to improve the effectiveness of healthcare delivery.

Community Health Information Network (CHIN). A system of communication created for use by health professionals, patients, and the community that links together hospital information systems with medical databases, community health information, and online computer services.

Computerized Provider Order Entry (CPOE). A computer application that allows a physician's orders for diagnostic and treatment services to be entered electronically. After entry, the computer compares the order against standards for dosing, checks for allergies or interactions with other medications, and warns the physician about any possible problems.

Connecting for Health. Connecting for Health was established by the Markle Foundation and receives additional funding and support from the Robert Wood Johnson Foundation. It is a public-private collaborative designed to address the barriers to the development of an interconnected health information infrastructure.

Consolidated Health Informatics (CHI) initiative. One of the 24 presidential (Office of Management and Budget) eGov initiatives, a collaborative effort to adopt health information interoperability standards, particularly health vocabulary and message standards, for implementation in federal government systems. CHI has adopted 20 uniform standards for electronic exchange of clinical information, and about 20 federal departments and agencies, including the Department of Health and Human Services, the Department of Defense, and the Department of Veterans Affairs, are active in the CHI governance process. CHI is an element of the Federal Health Architecture Program found in ONCHIT.

Continuity of Care Record (CCR). A standard specification being developed jointly by ASTM International, the Massachusetts Medical Society, the Health Information Management and Systems Society, the American Academy of Family Physicians, and the American Academy of Pediatrics. The CCR's purpose is to foster and improve continuity of patient care, reduce medical errors, and ensure at least a minimum standard of health information transportability when a patient is referred or transferred to another provider.

Current Procedural Terminology (CPT). Developed by the American Medical Association, these are codes used for the billing of medical procedures; they are updated annually.

Database. A store of data that describe entities and the relationships between the entities.

Data compression. A way of reducing the volume of data through the use of more efficient encoding practices. Compression reduces image processing, transmission times, bandwidth requirements, and storage space requirements.

Data encryption. A way to achieve data security that involves translating data into a secret code. Reading an encrypted file involves having a secret key or password that allows decryption.

Data Encryption Standard (DES). A method of data encryption using a private key. This widely used method was judged so difficult to break by the U.S. government that it was restricted for exportation to other countries.

Data format. Refers to the form of the data in a database. Data items can exist in many formats such as text, integer, and floating-point decimal.

Database management system (DBMS). A collection of software that can be used to create, maintain, and work with databases. Currently, DBMSs can manage data in any form, including text, images, sound, and video.

Data mining. Extracting information with the goal of discovering hidden facts contained in databases. Data mining finds patterns and subtle relationships in data and infers rules that allow the prediction of results.

Data repository. The element of an information system that accepts, files, and stores data from various sources.

Data warehouse. A collection of data gathered from one or more data repositories to create a central database. Data warehousing also includes the architecture and tools needed to collect, query, analyze, and present information.

Decision support system (DSS). Computer tools or applications that help physicians make clinical decisions by providing evidence-based knowledge in the context of data that is specific to the patient. Examples include drug interaction alerts at the time medication is prescribed and reminders for guideline-based interventions when caring for patients with chronic disease.

Digital Imaging and Communications in Medicine (DICOM). A standard developed for the transmission of images by the joint committee of the American College of Radiology and the National Electrical Manufacturers Association. DICOM is vendor independent. DICOM 3.0 is the current version.

Digital Rights Management (DMR). As in DRM system, which can be used to protect private information in health records from third parties. A DRM policy could allow insurance companies to review only the part of the record needed to authorize coverage, while not allowing the record to be saved on the company's server. The technology also can alert patients regarding who has accessed what information.

DoCDat. A directory of clinical databases in the United Kingdom that provides a brief description of each database, including what it covers and how it is managed. It provides a simple review of the quality of the data and contact details for the custodian of each database.

Electronic data interchange (EDI). A general term describing the need for healthcare applications to be able to exchange data. It requires the adoption of agreed common standards for the form and content of the messages passing between applications.

Electronic prescribing (eRx). A type of computer technology in which physicians use handheld or personal computers to review drug and formulary coverage and to send prescriptions to a printer or to a local pharmacy.

Extensible Markup Language (XML). XML is a meta-language written in Standard Generalized Markup Language (SGML). It allows for the interchange of documents on the Internet.

Federal Health Architecture (FHA). A collaborative body composed of many federal departments and agencies, including the Department of Health and Human Services (the sponsoring agency), the Department of Homeland Security, the Department of Veterans Affairs, the Environmental Protection Agency, the U.S. Department of Agriculture, the Department of Defense, and the Department of Energy. Its main goal is to improve coordination and collaboration on national health information technology solutions. FHA is a program of ONCHIT. Nearly all agencies involved in the healthcare industry participate in the FHA, and 15 federal departments/agencies participate in the FHA Partner Council.

Federally Qualified Health Centers (FQHC). A type of provider defined by the Medicare and Medicaid statutes. FQHCs include all organizations receiving grants under section 330 of the Public Health Service Act, certain tribal organizations, and what are known as FQHC Look-Alikes.

Health Care Information Standards Planning Panel (HISPP). Established by ANSI, this panel coordinates the evolution of standards using standard-setting organizations in healthcare.

Healthcare Information and Management Systems Society (HIMSS). The healthcare industry's membership organization is focused on providing leadership for the optimal use of healthcare information technology and management systems to improve human health.

Health Information Standards Board (HISB). A subgroup of ANSI, this board provides a public forum for the voluntary coordination of healthcare informatics standards among all U.S. standard-developing organizations. Every major developer of healthcare informatics standards in the United States participates in the ANSI HISB.

Health information technology (HIT). The application of information processing (both computer hardware and software) that deals with the storage, retrieval, sharing, and use of healthcare information, data, and knowledge for communication and decisionmaking.

Health Insurance Portability and Accountability Act of 1996 (HIPAA). A federal law that allows persons to qualify immediately for comparable health insurance coverage when they change their employment relationships. Title II, Subtitle F of HIPAA gives the Department of Health and Human Services the authority to mandate the use of standards for the electronic exchange of healthcare data; to specify what medical and administrative code sets should be used within those standards; to require the use of national identification systems for healthcare patients, providers, payers, and employers; and to specify the types of measures required to protect the security and privacy of personally identifiable healthcare information. Also known as the Kennedy-Kassebaum Bill or PL 104-191.

Health Level 7 (HL7). An international standard for electronic data exchange in healthcare that defines the format and content of messages that pass between medical applications. HL7 messaging standards are endorsed by the Department of Health and Human Services. HL7 is supported by every major medical informatics system vendor in the United States. Health Level Seven (HL7) also refers to one of several American National Standards Institute's-accredited Standards Developing Organizations (SDOs) operating in the healthcare arena.

Integrated system. An integrated system has multiple components, each of which may have a different function, but all of which follow a common architecture and set of operating principles and work together.

The International Classification of Diseases, Ninth Edition, Clinical Modification (ICD-9-CM). Based on the World Health Organization's Ninth Revision, International Classification of Diseases (ICD-9). ICD-9-CM is the official system of assigning codes to diagnoses and procedures associated with hospital utilization in the United States. The ICD-9 is used to code and classify mortality data from death certificates. The Department of Health and Human Services had been considering a proposal that healthcare providers adopt the ICD-10-CM classification system.

International Organization for Standardization (ISO). A network of the national standards institutes of 148 countries, with a Central Secretariat in Geneva, Switzerland that coordinates the system. A nongovernmental organization and the world's largest developer of standards.

Institute of Medicine (IOM) Committee on Patient Safety Data Standards. Group within IOM that produces a detailed plan to facilitate the development of data standards that apply to the collection, coding, and classification of patient safety information.

Interoperability. Systems that are interoperable may function in different ways, but they can work together, whether by sharing data or a common user interface. The National Alliance for Health Information Technology has proposed a definition for the term "interoperability" and is seeking comment on it in an effort to guide the creation of interconnected clinical systems. It defines interoperability as "the ability of different information technology systems, software applications and networks to communicate, to exchange data accurately, effectively and consistently, and to use the information that has been exchanged."

Joint Commission on Accreditation of Healthcare Organizations (JCAHO). An independent, not-for-profit organization healthcare organization that evaluates and accredits more than 15,000 healthcare organizations and programs in the United States.

Logical Observation Identifiers, Names, and Codes (LOINC). A clinical term for the electronic exchange of clinical laboratory results endorsed by the Department of Health and Human Services. LOINC was designed to be compatible with HL7 messages and has been endorsed by the American Clinical Laboratory Association and the College of American Pathologists. LOINC is one of a group of designated standards for use in U.S. federal government systems for the electronic exchange of clinical health information. The National Library of Medicine supports the ongoing development of LOINC through a contract arrangement.

MedBiquitous. ANSI-accredited developer of information technology standards for healthcare education and competence assessment.

Medicare Prescription Drug Improvement and Modernization Act (MMA) of 2003. Requires the Centers for Medicare and Medicaid Services to develop standards for electronic prescribing, which is a first step toward the widespread use of electronic health records. It also requires the establishment of a Commission on Systemic Interoperability to provide a roadmap for interoperability standards.

MedLEE. Medical Language Extraction and Encoding System (currently a research project) at Columbia University.

Middleware. Describes software that connects other software together. Middleware has either been custom-coded for individual projects or has come in the form of proprietary products; however, standards-based distributed middleware is emerging.

National Alliance for Health Information Technology (NAHIT). A partnership of leaders from all healthcare sectors that is working to advance the adoption and implementation of healthcare information technology to achieve measurable improvements in patient safety, quality, and efficiency. The alliance brings together high-level executives from a wide range of healthcare organizations to agree on standards and share ideas for implementing technology. Its more than 75 members include the American Hospital Association, the American Medical Association, the American Health Information Management Association, Blue Cross and Blue Shield Association, and Siemens Medical Solutions USA.

National Alliance for Primary Care Informatics (NAPCI). A coordinating group of primary care organizations working to develop and implement a national strategy for the use of information technology and management in primary care.

National Committee for Quality Assurance (NCQA). A private, 501(c)(3) not-for-profit organization dedicated to improving healthcare quality and helping to inform healthcare choices by generating useful, understandable information about healthcare quality for consumers and employers.

National Committee on Vital and Health Statistics (NCVHS). The Department of Health and Human Service's statutory public advisory body, composed of private sector experts on health data, statistics, and national health information policy.

National Council for Prescription Drug Programs (NCPDP). NCPDP creates and promotes data interchange and processing standards for the pharmacy services sector of the healthcare industry, including those for billing pharmacy claims and services, rebates, pharmacy ID cards, and for business functions between prescribers and pharmacies (e-prescribing).

National Drug File Reference Terminology (NDF-RT) and RxNorm. These projects are focused on improving the interoperability of drug terminology. The NDF-RT is being developed for the Department of Veterans Affairs as a reference standard for medications to support a variety of clinical, administrative, and analytical purposes. The National Library of Medicine is developing the RxNorm Project to add new concepts to the UMLS for clinical drug representations.

National Health Information Infrastructure (NHII). Refers to the development of a comprehensive knowledge-based network of interoperable systems of clinical, public health, and personal health information. This network would improve medical care and decisionmaking by enabling healthcare providers access to current electronic health records for patients who have authorized it, whenever and wherever the patient receives care.

National Health Information Network (NHIN). The actual network that would be created to link disparate healthcare information systems together in order to allow patients, physicians, hospitals, public health agencies, and others to share clinical information in real time.

National Institute of Standards and Technology (NIST). A nonregulatory federal agency within the U.S. Commerce Department's Technology Administration, NIST works to develop and promote measurement, standards, and technology to enhance productivity, facilitate trade, and improve the quality of life.

National Institutes of Health (NIH). NIH has a strong focus on the use of electronic clinical data for the purposes of research. It supports numerous clinical studies that rely on an EMR or a partial clinical dataset for research and has provided more than $128 million for development and research related to clinical research networks.

National Library of Medicine (NLM). The world's largest medical library. Performs research and development in medical informatics. Maintains Medline. NLM produces and distributes the UMLS Knowledge Sources (databases) and associated software tools.

National Science Foundation (NSF). An independent federal agency created by Congress in 1950 "to promote the progress of science; to advance the national health, prosperity, and welfare; to secure the national defense…." It is the funding source for about 20 percent of all federally supported basic research conducted by America's colleges and universities.

Natural language processing (NLP). Natural Language Processing is the name for a sub-field of Artificial Intelligence studies in computer science. NLP deals with the parsing, processing, and analysis of human language to map it into a machine-usable format (for a database, for writing program code, or for issuing commands to control software or systems) or by extension to translate between one language (set of jargon, grammar, and vocabulary) and another.

Nomenclature. An agreed-upon system of assigned names.

Office of the National Coordinator for Health Information Technology (ONCHIT). Provides national leadership to support efforts across government and in the private sector to develop the standards and infrastructure needed to support more effective use of information technology in order to promote higher quality healthcare and reduce healthcare costs.

openEHR. An international not-for-profit foundation working toward the development of interoperable, life-long electronic health records and toward understanding the social, clinical, and technical challenges of electronic records for healthcare. openEHR develops open source specifications, software, and knowledge management resources, engages in clinical implementation projects, participates in international standards development, and supports health informatics education.

OpenGALEN. GALEN is a technology for medical coding and terminology that was designed as a new kind of infrastructure for clinical application builders. OpenGALEN is a non-for-profit organization that is working to bring GALEN to the world as an open source resource.

Open source software (OSS). Programs whose licenses give users the freedom to run them for any purpose, to study and modify them, and to redistribute copies of them (original or modified) without having to pay royalties to previous developers.

Open standards. Open standards are available when the rules for a certain technology are openly published and available so that everyone can write software or build hardware that follows them. Most open source software follows open standards, if such standards exist.

Personal digital assistant (PDA). A handheld computer that allows an individual to store, access, and organize information. Most PDAs work on either a Windows-based or a Palm operating system. PDAs can be screen-based, keyboard-based, or both.

Physicians' Electronic Health Record Coalition (PEHRC). Includes 14 medical organizations, representing more than 500,000 U.S. physicians. It helps physicians, especially those in small- and medium-size ambulatory care practices, to acquire and use affordable, standards-based electronic health records and other health information technology.

President's Information Technology Advisory Committee (PITAC). Chartered by Congress under the High-Performance Computing Act of 1991 (PL 102-194) and the Next Generation Internet Act of 1998 (PL 105-305), PITAC is a Federal Advisory Committee, providing advice to the President, Congress, and the federal agencies involved in information technology research and development.

Problem-oriented medical record (POMR). A medical record in which the notes are recorded for each problem assigned to the patient. Lawrence L. Weed introduced the POMR in the late 1960s to improve the structure of medical records.

Protected health information (PHI). As defined under HIPAA, individually identifiable health information transmitted by electronic media, maintained in electronic media, or transmitted or maintained in any other form or medium. PHI excludes education records covered by the Family Educational Rights and Privacy Act, as amended, 20 USC 1232g, records described at 20 USC 1232g(a)(4)(B)(iv), and employment records held by a covered entity in its role as employer.

Protocol. A system of guidelines and procedures (applying to both hardware and software) that oversees communications between two computer devices.

Public key infrastructure (PKI). A PKI enables users of an unsecure public network, such as the Internet, to securely and privately exchange data and money through the use of a public and a private cryptographic key pair. A number of different vendor approaches and services are emerging, and an Internet standard for PKI is under development.

Quality Improvement Organizations (QIOs). Medicare QIOs work with consumers, physicians, hospitals, and other caregivers to refine care delivery systems to make sure patients get the proper care. They also help safeguard the integrity of the Medicare trust fund by ensuring that payment is made only for medically necessary services. Under the direction of the Centers for Medicare and Medicaid Services, the program consists of a national network of 53 QIOs responsible for each U.S. state, territory, and the District of Columbia.

Regional Health Information Organizations (RHIOs). Previously known as community health information networks (CHINs), a RHIO connects doctors, hospitals, and others in a community so that they can share information electronically. RHIOs are multistakeholder organizations that work together to connect healthcare communities in order to improve care.

Relational database. A collection of data items organized as a set of formally described tables from which data can be accessed or reassembled in many different ways without having to reorganize the database tables. Relational databases are relatively easy to create and access. They are also easy to extend, because a new data category can be added without modifying all existing applications. Most relational databases use structured query language (SQL).

Relational database management system (RDBMS). A type of database management system (DBMS) that stores data in the form of related tables. In a relational system, a single database can be spread across several tables, while in flat-file databases each database is self-contained in a single table. Almost all full-scale database systems are RDBMSs.

Research Patient Data Registry (RPDR) from Harvard University. A system incorporating patient information from Massachusetts General Hospital and Brigham and Women's Hospital, combining anonymized searching capabilities for research with (when authorized by an Institutional Review Board) the ability to extract patient-identifiable information on medical histories, diagnoses, medications, treatments, billing, and more.

Standards Developing Organizations (SDOs). SDOs generally produce standards (sometimes called specifications or protocols) for a particular healthcare domain, such as pharmacy, medical devices, imaging, or insurance transactions. Also known as standard setting organizations (SSOs).

"Stark law." Prohibits physician compensation based on the volume or value of referrals for most major ancillary and hospital services as well as for key medical and nutritional products. On March 26, 2004, the government released the latest version of Stark II, which states that one cannot refer Medicare or Medicaid patients for certain services with which a provider or an immediate family member has a financial relationship, unless an exception applies. There are 11 categories of covered services that are subject to referral restrictions. In the area of EMRs, the Stark law has implications for accepting software from certain entities.

Structured query language (SQL). An ANSI standard computer language for accessing and manipulating databases.

Systematized Nomenclature of Medicine-Clinical Terms (SNOMED-CT). A medical vocabulary owned by the College of American Pathologists and endorsed by the Department of Health and Human Services. In 2003, the Department of Health and Human Services announced an agreement with the College of American Pathologists to make SNOMED-CT available to U.S. users at no cost through the National Library of Medicine's Unified Medical Language System.

Telehealth. The use of electronic communications networks for the transmission of information and data involving healthcare. Most do not see clear-cut distinctions between telehealth and telemedicine, although some consider telehealth to be broader in scope.

Telemedicine. The delivery of healthcare services to people who are at distant sites through the use of audio, video, and other telecommunications and electronic information technologies. Telemedicine is used to transmit photographs, x-ray images, and patient records, and more, or to hold videoconferences.

Triple modular redundant (TMR) systems. Any kind of database system can be a TMR system, which replicates data and processing on three "nodes."

Two-factor authentication. Two methods are required for log-in to access electronic information, such as both a smart card and a password (something you have and something you know).

Unified Medical Language System (UMLS). This language system was designed to facilitate the development of computer systems that behave as though they understand the meaning of the language of biomedicine and health. The National Library of Medicine produces and distributes the UMLS Knowledge Sources (databases) and associated software tools for use by system developers in building or enhancing electronic information systems that create, process, retrieve, integrate, and/or aggregate biomedical and health data and information.

User interface. The graphic and design elements of a computer program or Web page that tell users how to access the information contained in that program or on that site.

Value-added network (VAN). A private network provider that is hired by a company to facilitate electronic data interchange or provide other network services.

Veterans Health Information Systems and Technology Architecture (VistA). Used by the Department of Veterans Affairs. A collection of about 100 integrated software modules that cover healthcare applications, from patient records to admissions and billing. Supports both ambulatory and inpatient care.

Virtual private network. A technical strategy for creating secure connections over the Internet.

X12N. Dominant standard for electronic commerce. American National Standards Institutes Accredited Standards Committee X12 (ASC X12) selected X12N as the standard for electronic data interchange to be used in administrative and financial healthcare transactions (excluding retail pharmacy transactions) in compliance with HIPAA.

Appendix D

Federal Agencies and the Electronic Medical Record

Much of the momentum in the adoption of the electronic medical record (EMR) has been spurred on by a number of federal government agencies that have created electronic systems for improving patient care, claims processing, and payment. The upfront costs for network and hardware upgrades can be substantial, which is why federal agencies have historically been the only entities with enough cash to launch such efforts.

Much of the federal investment has been in converting federal healthcare providers, such as the Veterans Health Administration (VHA), the Department of Defense's (DOD's) TRICARE network, and the Indian Health Service (IHS), to fully electronic systems. Other agencies, such as the Agency for Healthcare Research and Quality (AHRQ) and the Centers for Medicare and Medicaid Services (CMS), support conversion efforts or maintain large databases with beneficiary, actuarial, and claims data.

The most compelling reason for federal healthcare providers to convert to the EMR is patient safety. Abundant evidence demonstrates that medication errors, the primary cause of iatrogenic injury, can be dramatically reduced by the use of computerized provider order entry. The EMR also allows for consistent access to the medical record. Timely data entry is another advantage of electronic records. Most of the data are entered directly by the user (e.g., nurse, provider, pharmacist) at the point of service. All documentation that has been electronically signed is immediately available to other users. The use of professional coders will have an important role to play in educating, supporting, and monitoring providers who will have increasing responsibility for coding compliance. Thus, for VHA, IHS, and DOD, the EMR provides greater efficiencies; however, for most of these efforts research is not the primary focus.

There are, however, some federal efforts aimed at using electronic records (typically partial records) for research purposes. Most often the research has a health services focus—for example, studying facility use, outcomes, and costs. CMS maintains numerous large databases that are available under controlled conditions to researchers, as does the Centers for Disease Control and Prevention. Recently, CMS and VHA collaborated to configure VistA, VHA's Electronic Healthcare Record (EHR) technology, to the private physician office setting. VistA-Office EHR, a public-domain solution to supplement EMRs available from private vendors, will include the existing VistA functions of order entry, documentation, and results reporting. The expected release date is July 2005. Through this effort, CMS and VHA are helping to stimulate adoption of EMRs in the physician office setting by encouraging the use of private sector vendor EMRs that are affordable, high quality, interoperable, and standards-based.

AHRQ has launched some pilot projects to study the development and adoption of health information technology. Even the Food and Drug Administration (FDA) is anticipating the increasing use of electronic data records and sets for clinical research. In October 2004, FDA announced the availability of draft guidance about computerized systems that are used to create, modify, maintain, archive, retrieve, or transmit clinical data required to be maintained and/or submitted to FDA. And FDA is currently seeking volunteers to participate in a pilot project involving the evaluation of various analysis tools to facilitate the use of electronic datasets for analysis of animal and human data submitted to FDA.

The National Institutes of Health (NIH) is the agency most focused on the use of electronic clinical data for the purposes of research. In addition to supporting numerous clinical studies that rely on an EMR or partial clinical dataset for research, NIH has provided more than $128 million for development and research related to "clinical research networks." The Clinical Research Networks facet of NIH's Re-engineering the Clinical Research Enterprise Roadmap will promote and expand clinical research networks that can rapidly conduct high-quality clinical studies that address multiple research questions. An inventory of existing clinical research networks will explore existing informatics and training infrastructures in order to identify characteristics that promote or inhibit successful network interactivity, productivity and expansion, or broadening of research scope. However, it is anticipated that although the inventory will be fairly comprehensive, it will capture only approximately five percent of the U.S. patient population—that is, those individuals who are already involved in clinical trials, not the typical practice population.

Finally, the National Health Information Infrastructure (NHII), is focused on information availability and sharing at the local and national levels and is about electronically exchanging healthcare information securely. It addresses the domains of the consumer, the healthcare provider, and population health (including clinical research, although the extent of that commitment is not clear). As the NHII grows, it will play an important role with regard to research, but it is not certain at this point whether that role will be enabling or inhibiting.

Appendix E

State-Level Electronic Medical Record Efforts

State EMR Initiatives

State/Initiative	Organization/Members	Scope/Status	Funding
Kentucky	*Bill signed into law in May of 2005 approving development of a statewide network for exchange of patient information electronically among physicians, hospitals, insurers, and others*	*Goal of becoming the backbone of the national health information network by serving as a pilot site. Foresees emerging local and Regional Health Information. Organizations (RHIOs) connecting to its network*	*Not completely funded; seeking federal and private funding. Business model is needed to ensure effort is self-sustaining*
Maine	*Nine-member Commission to Study Maine Hospitals recommended in early 2005 that a statewide electronic medical record (EMR) system should be created under the leadership of the Maine Quality Forum*	*Part of a larger plan to reduce hospital costs while improving quality and access*	*Some state support to be provided*
Massachusetts *Massachusetts e-Health Collaborative www.maehc.org*	*Nonprofit collaborative, 34 partners (providers/health plans/insurers)*	*Has begun conducting large-scale regional health pilots in three Massachusetts communities*	*Blue Cross Blue Shield providing $50 million in seed funding to back the pilots*
Michigan *Michigan Electronic Medical Record Initiative (MEMRI) www.memri.us/faq.html*	*Nonprofit corporation coalition of physicians, hospitals, and technology companies*	*Developing a statewide system featuring decentralized data, with EMRs stored temporarily and assembled in real time; permanent records will stay with providers. Hopes to become a national model*	*Supported by a variety of for-profit and not-for-profit organizations*
Nebraska	*Health Partners Initiative is a partnership of Southeast Nebraska medical providers*	*Study of how to create a regional system to share mental health records. First step involves looking at systems to determine what is needed to enable exchange of information*	*Funded by a $200,000 grant from the federal government that covers providers in 16 Southeast Nebraska counties*
New Jersey	*Launched by the New Jersey Department of Banking and Insurance*	*Effort to create statewide EMR to enable physicians to share patients' medical records*	*Initiated May of 2005*
Oregon	*Oregon Senate passed bill in May of 2005 to establish a task force to help develop and implement a statewide EMR system*	*Would bring together hospitals, physician offices, and vendors to develop a system*	*Bill passed in May of 2005*
Pennsylvania *Pennsylvania e-Health Technology Consortium*	*Consortium of 28 healthcare organizations (physician organizations, hospital systems, state agencies, insurers)*	*Coordinated effort to develop electronic information sharing statewide by seeking grants and hosting forums for hospital CIOs and physicians who have adopted EMRs. Has been charged by CMS with fostering the Pennsylvania-based electronic networks, or RHIOs*	*Has formed governance and finance committees, seeking federal support. Not clear if health insurers will be providing support*
Wisconsin	*A new State Health Care Quality and Patient Safety Board*	*Development of a plan to automate all healthcare information systems in the state by 2010*	*$10 million grant and loan program to reduce medical errors and healthcare costs, with grants and loans going to clinics, HMOs, and hospitals*

Additional Information on Selected States

Arkansas Many of Arkansas' largest hospitals use electronic medical records (EMRs) or plan to implement them in the near future. Arkansas Blue Cross Blue Shield, which has the most advanced technology in the Blue Cross network, has contributed to increased use of EMRs in Arkansas.

However, although Arkansas has received federal assistance and more physicians are converting to EMRs, few of its many rural and critical-access hospitals are using EMRs, mainly because of a lack of funds. Software compatibility also is a barrier for adoption.

Maine In December 2004, a hospital commission in Maine recommended that the state create a statewide EMR system that would allow for electronic access to patients' records, including medical histories, medication lists, and other related information. The nine-member Commission to Study Maine Hospitals' plan is part of a larger group of recommendations to reduce hospital costs while improving quality and access to care.

The commission was created by Governor John Baldacci and is composed of hospital administrators, providers, insurers, businesses, and consumers. The plan to create a statewide EMR system would let healthcare workers view patient records from any hospital. Some organizations, such as Eastern Maine Healthcare Systems, already are implementing EMRs, but smaller hospitals are still using paper.

Massachusetts On December 6, 2004, Governor Mitt Romney announced that Massachusetts aims to be the first state with an EMR system. The Massachusetts eHealth Collaborative is a nonprofit consortium of 34 institutions statewide, including hospitals, insurers, business associations, and physician groups, and the eHealth project has been launched as a pilot program in three communities—Greater Brockton, Greater Newburyport, and Northern Berkshire—with the goal of having a statewide system in place within five years. The Collaborative aims to improve the safety, cost-effectiveness, and quality of healthcare in Massachusetts through the promotion of widespread implementation and use of electronic clinical information systems, including EMRs, medical decision support, and clinical data exchange capabilities.

Blue Cross Blue Shield of Massachusetts is providing $50 million in funding toward the project that the Collaborative will use to buy and install interoperable EMR software with clinical decision support in physician offices. The money also will pay for hardware, implementation services, system integration services, technology support and maintenance, and linkages between doctors, hospitals, and other healthcare professionals.

Massachusetts officials believe that financing has been a barrier to implementation of such initiatives because the burden of financing has been on physicians and practices, while the financial benefits predominantly go to the purchasers of healthcare and insurers. If the Collaborative is to succeed in getting Massachusetts doctors to integrate EMRs into their practices, it must develop ways to make the systems affordable for physicians. Thus, the pilots will be used to quantify the clinical and financial benefits of using EMRs and the cost of implementing a statewide network.

The Collaborative also will use data gathered from the pilots to devise a financing or payment mode that can address the high start-up and ongoing costs that often deter physicians from adopting EMRs. However, the plan will not offer annual bonuses or higher reimbursement rates to encourage doctors to use information technology, because these have not been successful in the past.

Several work groups have been formed for program and design purposes, but none seem to be focused on research.

Nevada In December 2004, North Vista Hospital in Nevada launched an electronic patient records system that will enable hospital workers to access patient records in real-time, remotely and simultaneously.

North Vista was the first of IASIS Healthcare's 15 hospitals to transition to an electronic records system. IASIS also has designated $40 million to convert its hospitals in Arizona, Utah, Florida, and Texas to the system. North Vista is the seventh of 11 hospitals in the Las Vegas area to implement an EMR system.

The hospital will use mobile computers to update records from patient rooms, and the system is linked to medical devices such as ventilators, diagnostic equipment, and cardiac monitors for continuous updating. The system also issues electronically generated lists to remind nurses to administer medications and perform other tasks.

Four other hospitals in the Las Vegas Valley, owned by Universal Health Services, are adopting EMRs in various stages. By the end of next year, all of the hospitals will have the real-time system, and the EMR initiatives will be completed at 90 percent of the hospitals during 2006.

Ohio Many Dayton, Ohio, area hospitals are moving toward adopting an EMR, including Middletown Regional Hospital, which is spending millions of dollars on software and equipment for EMR systems. Many hospitals also are investing in wireless networks that will allow doctors and nurses to connect to the systems from mobile devices. Others are installing computers in hospital rooms.

Premier Health Partners plans to spend more than $30 million on its EMR system project, which will make Miami Valley and Good Samaritan Hospitals wireless and which includes installing software and hardware at all of Premier's subsidiaries. The first hospital will use the system in early 2006.

Kettering Medical Center Network, which includes Kettering Memorial Hospital, Grandview Hospital, and Southview Hospital, plans to spend more than $15 million on a new electronic records system, while Children's Medical Center plans to invest almost $10 million over the next six years to implement a system.

Larger physician practices also are exploring the option of electronic records. The Dayton Heart Center, with 4 offices and 16 physicians, launched electronic records more than 2 years ago. Charlie Walker, the practice's executive director, said it is a "major, six-figure expense" for most cardiology groups to invest in a system. For a small practice of three to four doctors, it is not feasible, he said, noting that the Heart Center bought a system developed strictly for cardiologists.

Appendix F

Selected Electronic Medical Record System and Related Health Information Technology Resources

A. Standards and Standards-Setting Organizations

American National Standards Institute (ANSI)
www.ansi.org A voluntary organization of more than 1,300 members that creates standards for the computer industry, including standards for programming languages and in technical areas ranging from electrical specifications to communications protocols.

American Society for Testing and Materials International (ASTM)
www.astm.org A component of the American National Standards Institute, with an E31 subcommittee for general healthcare informatics. ASTM develops voluntary consensus standards, related technical information, and services related to the architecture, content, storage, security, confidentiality, functionality, and communication of information used within healthcare.

ASTM Committee E31 on Healthcare Informatics
www.astm.org/cgi-bin/SoftCart.exe/COMMIT/COMMITTEE/E31.htm?E+mystore Develops standards related to the architecture, content, storage, security, confidentiality, functionality, and communication of information used within healthcare and healthcare decisionmaking.

Current Procedural Terminology (CPT)
www.ama-assn.org/ama/pub/category/3113.html Developed by the American Medical Association, these are codes used for the billing of medical procedures, updated annually.

Digital Imaging and Communications in Medicine (DICOM)
www.xray.hmc.psu.edu/physresources/dicom/basicinfo.html
A standard developed for the transmission of images by the joint committee of the American College of Radiology and the National Electrical Manufacturers Association. DICOM is vendor-independent. DICOM 3.0 is the current version.

Health Care Information Standards Planning Panel (HISPP)
Established by ANSI, this panel coordinates the evolution of standards using standards-setting organizations in healthcare.

Health Information Standards Board (HISB)
www.ansi.org/standards_activities/standards_boards_panels/hisb/overview.aspx?menuid=3 A subgroup of the American National Standards Institute, this board provides a public forum for the voluntary coordination of healthcare informatics standards among all U.S. standards-developing organizations. Every major developer of healthcare informatics standards in the United States participates in ANSI HISB.

Health Level 7 (HL7)
www.hl7.org An international standard for electronic data exchange in healthcare that defines the format and content of messages that pass between medical applications. HL7 messaging standards are endorsed by the Department of Health and Human Services. HL7 is supported by every major medical informatics system vendor in the United States. Health Level Seven (HL7) also refers to one of several American National Standards Institute's-accredited Standards Developing Organizations (SDOs) operating in the healthcare arena.

The HL7 Electronic Health Record (EHR) Technical Committee's Home Page *www.hl7.org/ehr*
A gateway for information related to the ongoing HL7's Electronic Health Record Systems standards development work; provides information on the model EHR standard.

The model EHR standard
www.hl7.org/ehr/documents/public/documents/FunctionsOutline.asp

Institute of Electrical and Electronics Engineers (IEEE) Standards Development Program
standards.ieee.org/resources/index.html The IEEE Standards Association has more than 8,350 individual and almost 60 corporate members.

Institute of Medicine (IOM) Committee on Patient Safety Data Standards
www.iom.edu/psds Group within IOM that produces a detailed plan to facilitate the development of data standards that apply to the collection, coding, and classification of patient safety information.

The International Classification of Diseases, Ninth Edition, Clinical Modification (ICD-9-CM)
www.who.int/classifications/icd/en Based on the World Health Organization's Ninth Revision, International Classification of Diseases (ICD-9). ICD-9-CM is the official system of assigning codes to diagnoses and procedures associated with hospital utilization in the United States. The ICD-9 is used to code and classify mortality data from death certificates. The Department of Health and Human Services had been considering a proposal that healthcare providers adopt the ICD-10-CM classification system.

Logical Observation Identifiers, Names, and Codes (LOINC)
www.nlm.nih.gov/research/umls/loinc_main.html
A clinical term for the electronic exchange of clinical laboratory results endorsed by the Department of Health and Human Services. LOINC was designed to be compatible with HL7 messages and has been endorsed by the American Clinical Laboratory Association and the College of American Pathologists. LOINC is one of a group of designated standards for use in U.S. federal government systems for the electronic exchange of clinical health information. The National Library of Medicine supports the ongoing development of LOINC through a contract arrangement. LOINC information is available from the Regenstrief Institute (www.regenstrief.org), which produces LOINC and maintains the LOINC database and its supporting documentation.

MedBiquitous
www.medbig.org American National Standards Institute-accredited developer of information technology standards for healthcare education and competence assessment.

National Council for Prescription Drug Programs (NCPDP)
www.ncpdp.org NCPDP creates and promotes data interchange and processing standards for the pharmacy services sector of the healthcare industry, including those for billing pharmacy claims and services, rebates, pharmacy ID cards, and for business functions between prescribers and pharmacies (e-prescribing).

National Drug File Reference Terminology (NDF-RT) and RxNorm
www.nlm.nih.gov/research/umls/rxnorm_main.html These projects are focused on improving the interoperability of drug terminology. The NDF-RT is being developed for the Department of Veterans Affairs as a reference standard for medications to support a variety of clinical, administrative, and analytical purposes. The National Library of Medicine is developing the RxNorm Project to add new concepts to the UMLS for clinical drug representations.

National Library of Medicine's Unified Medical Language System (UMLS)
www.nlm.nih.gov/research/umls This language system was designed to facilitate the development of computer systems that behave as though they understand the meaning of the language of biomedicine and health. The National Library of Medicine produces and distributes the UMLS Knowledge Sources (databases) and associated software tools for use by system developers in building or enhancing electronic information systems that create, process, retrieve, integrate, and/or aggregate biomedical and health data and information.

UMLS FAQ page
www.nlm.nih.gov/research/umls/faq_main.html

UMLS basics document
umlsinfo.nlm.nih.gov/UMLS_Basics.pdf

Systematized Nomenclature of Medicine-Clinical Terms (SNOMED-CT)
Snomed.org A medical vocabulary owned by the College of American Pathologists and endorsed by the Department of Health and Human Services. In 2003, the Department of Health and Human Services announced an agreement with the College of American Pathologists to make SNOMED CT available to U.S. users at no cost through the National Library of Medicine's Unified Medical Language System.

SNOMED-CT page
www.nlm.nih.gov/research/umls/Snomed/snomed_main.html

SNOMED-CT FAQS
www.nlm.nih.gov/research/umls/Snomed/snomed_faq.html

X12N
www.x12.org/x12org/index.cfm Dominant standard for electronic commerce. American National Standards Institutes Accredited Standards Committee X12 (ASC X12) selected X12N as the standard for electronic data interchange to be used in administrative and financial healthcare transactions (excluding retail pharmacy transactions) in compliance with HIPAA.

For an extensive list of links to content and vocabulary datasets, technology and community standards, and a variety of other standards-related sites, including organizations that set standards, see *integrateforhealth.com/UsefulLinks/index.htm*.

B. Federal Government Health Information Technology Agencies and Initiatives

Agency for Healthcare Research and Quality (AHRQ)
www.ahrq.gov AHRQ has launched some pilot projects to study the development and adoption of health information technology. In September 2004, AHRQ awarded $139 million in contracts and grants to promote the use of health information technology programs.

List of projects funded by state
www.ahrq.gov/research/hitfact.htm Fact Sheet

Bureau of Primary Health Care (BPHC), Health Resources and Services Administration
bphc.hrsa.gov/chc/CHCInitiatives/emr.htm From 2001 to 2003, the Bureau of Primary Health Care sponsored two pilot projects for electronic health records, the result of the Health Center Information Systems Workgroup's recommendations to provide community health centers with information on EMRs and disease management to assist with the implementation of systems that support clinical data management.

Centers for Medicare and Medicaid Services (CMS)
www.cms.hhs.gov The Department of Health and Human Services agency responsible for Medicare and parts of Medicaid. CMS also is responsible for oversight of HIPAA administrative simplification transaction and code sets, health identifiers, and security standards.

Centers for Medicare and Medicaid Services Physician Focused Quality Initiatives.
www.cms.hhs.gov/quality/pfqi.asp These include some initiatives related to healthcare information technology, including the Doctor's Office Quality Information Technology (DOQ-IT) Project, VistA-Office EHR, and several Demonstration Projects and Evaluation Reports.

Doctors' Office Quality-Information Technology (DOQ-IT)
www.doqit.org/doqit/jsp/index.jsp Promotes the adoption of EHR systems and information technology in small- to medium-sized physician offices. The two-year Special Study demonstration was initiated by the Centers for Medicare and Medicaid Services to offer an integrated approach to improving care for Medicare beneficiaries in the areas of diabetes, heart failure, coronary artery disease, hypertension, osteoarthritis, and preventive care.

VistA-Office EHR project
www.cms.hhs.gov/quality/VistAQsAs.pdf The Centers for Medicare and Medicaid Services and the Veterans Health Administration are helping to stimulate adoption of electronic health record systems in the physician office setting by encouraging the use of private-sector vendor electronic health records.

Demonstration Projects and Evaluation Reports page
www.cms.hhs.gov/researchers/demos One project that is related to healthcare information technology is the Medicare Care Management Project Demonstration Project, a three-year demonstration program that will reward physicians for adopting and using health information technology and evidence-based outcome measures to promote continuity of care, stabilize medical conditions, prevent or minimize acute exacerbations of chronic conditions, and reduce adverse health outcomes.

Consolidated Health Informatics (CHI) Initiative
www.whitehouse.gov/omb/egov/c-3-6-chi.html One of the 24 presidential (Office of Management and Budget) eGov initiatives, a collaborative effort to adopt health information interoperability standards, particularly health vocabulary and message standards, for implementation in federal government systems. CHI has adopted 20 uniform standards for electronic exchange of clinical information, and about 20 federal departments and agencies, including the Department of Health and Human Services, the Department of Defense, and the Department of Veterans Affairs, are active in the CHI governance process. CHI is an element of the Federal Health Architecture Program found in the Office of the National Coordinator for Health Information Technology.

Panel discussion on the CHI Initiative
www.iom.edu/Object.File/Master/11/046/0.doc

Department of Health and Human Services National Health Information Infrastructure FAQ
aspe.hhs.gov/sp/NHII/FAQ.html

Office of the National Coordinator for Health Information Technology (ONCHIT)
www.hhs.gov/healthit Provides national leadership to support efforts across government and in the private sector to develop the standards and infrastructure needed to support more effective use of information technology.

Information about Executive Order 13335, which established ONCHIT
www.whitehouse.gov/news/releases/2004/04/20040427-4.html

The Decade of Health Information Technology: Delivering Consumer-centric and Information-rich Health Care (the Framework)
www.hhs.gov/onchit/framework Outlined an approach toward the nationwide implementation of interoperable healthcare information technology in the public and private sectors.

ONCHIT's Request for Information to seek public comment regarding the widespread employment of EMRs
www.openhre.org/local/NHIN_RFI_OpenHRE.pdf

Department of Veterans Affairs (VA)
www.hhs.gov/healthit/attachment_2/v.html Information about the Department of Veterans Affairs and VistA (Veterans Health Information System and Technology Architecture) and electronic health records development.

Electronic Government Initiative (E-Government or E-Gov)
www.whitehouse.gov/omb/egov Instituted on July 10, 2002, E-Government involves using improved Internet-based technology to make it easy for citizens and businesses to interact with the government, save taxpayer dollars, and streamline citizen-to-government communications.

Transforming Health Care: The President's Health Information Technology Plan
www.whitehouse.gov/infocus/technology/economic_policy200404/chap3.html

Federal Health Architecture (FHA)
www.hhs.gov/fedhealtharch/visions.html A collaborative body composed of several federal departments and agencies, including the Department of Health and Human Services (the sponsoring agency), the Department of Homeland Security, the Department of Veterans Affairs, the Environmental Protection Agency, the Department of Agriculture, the Department of Defense, and the Department of Energy. FHA provides a framework for linking health business processes to technology solutions and standards and for demonstrating how these solutions achieve improved health performance outcomes. Its main goal is to improve coordination and collaboration on national health information technology solutions. FHA is a program of ONCHIT. Nearly all agencies involved in the healthcare industry participate in the FHA, and 15 federal departments/agencies participate in the FHA Partner Council.

Food and Drug Administration (FDA)
www.fda.gov This agency, in October 2004, issued draft guidance about computerized systems that are used to create, modify, maintain, archive, retrieve, or transmit clinical data required to be maintained and/or submitted to the agency.
See www.fda.gov/cder/guidance/6032dft.htm for the draft guidance.

Government Accountability Office (GAO)
www.gao.gov In "Information Technology: Benefits Realized for Selected Health Care Functions" (October 2003), identified cost savings and other benefits realized by healthcare organizations that have implemented information technology.
See www.gao.gov/new.items/d04224.pdf.

Indian Health Service Electronic Health Record (IHS EHR) Web site
www.ihs.gov/CIO/EHR

National Institutes of Health (NIH)
www.nih.gov NIH has a strong focus on the use of electronic clinical data for the purposes of research. It supports numerous clinical studies that rely on an EMR or a partial clinical dataset for research and has provided more than $128 million for development and research related to clinical research networks.

Clinical Research Networks facet of NIH's Re-engineering the Clinical Research Enterprise Roadmap overview
nihroadmap.nih.gov/clinicalresearch/index.asp

NIH Roadmap Web site
nihroadmap.nih.gov

National Committee on Vital and Health Statistics (NCVHS)
www.ncvhs.hhs.gov The Department of Health and Human Service's statutory public advisory body, composed of private-sector experts on health data, statistics, and national health information policy. NCVHS serves as a national forum for the collaboration of interested parties to accelerate the evolution of public and private health information systems toward more uniform, shared data standards, operating within a framework protecting privacy and security.

National Institute of Standards and Technology (NIST)
www.nist.gov A nonregulatory federal agency within the U.S. Commerce Department's Technology Administration, NIST's mission is to develop and promote measurement, standards, and technology to enhance productivity, facilitate trade, and improve the quality of life.

NIST's Advanced Technology Program (ATP)
www.atp.nist.gov Provides a mechanism for industry to extend its technological reach. Through partnerships with the private sector, ATP's early-stage investment is accelerating the development of innovative technologies that promise significant commercial payoffs and widespread benefits.

National Library of Medicine (NLM)
www.nlm.gov The world's largest medical library. Performs research and development in medical informatics. Maintains Medline. The National Library of Medicine produces and distributes the UMLS Knowledge Sources (databases) and associated software tools.

National Science Foundation (NSF)
www.nsf.gov An independent federal agency created by Congress in 1950 "to promote the progress of science; to advance the national health, prosperity, and welfare; to secure the national defense…." It is the funding source for about 20 percent of all federally supported basic research conducted by America's colleges and universities.

President's Information Technology Advisory Committee (PITAC)
www.itrd.gov/pitac Chartered by Congress under the High-Performance Computing Act of 1991 (PL 102-194) and the Next Generation Internet Act of 1998 (PL 105-305), PITAC is a Federal Advisory Committee, providing advice to the President, Congress, and the federal agencies involved in information technology research and development.

PITAC Reports:
Report to the President: Revolutionizing Health Care Through Information Technology President's Information Technology Advisory Committee (June 2004)
www.hpcc.gov/pitac/meetings/2004/20040617/20040615_hit.pdf

Report to the President: Cyber Security: A Crisis of Prioritization (February 2005)
www.itrd.gov/pitac/reports/20050301_cybersecurity/cybersecurity.pdf

For additional information and an extensive listing of current federal government initiatives, a Directory of Federal Health Information Technology Programs can be found at *www.hhs.gov/healthit/federalprojectlist.html#intitiativestable* (Office of the National Coordinator for Health Information Technology, Department of Health and Human Services).

C. Large Private-Sector Electronic Medical Record Systems

Geisinger Health System
www.geisinger.org

KaiserPermanente
Kaiser Permanente Northwest's work with Epic Systems in the development, implementation, maintenance, and continued improvement of the EMR
xnet.kp.org/permanentejournal/fall04/reality.html
xnet.kp.org/permanentejournal/fall04/reengine.html

Mayo Clinic
Several clinic webcasts on various subjects in medical informatics
www.mayo.edu/webcasts/arch_infogr.html

On Mayo Clinic and its electronic medical record system
www.mayoclinic.org/spotlight/electronicrecords.html.

Regenstrief Institute, Inc.
www.regenstrief.org
Information on Regenstreif, including the Regenstreif Medical Record System (RMRS), one of the first electronic medical record systems in the country *www.regenstrief.org/medinformatics/what*

Regenstrief publication list
www.regenstrief.org/medinformatics/pub

Regenstreif project list
www.regenstrief.org/medinformatics/projects

Sutter Health
www.sutterhealth.org

Plans to implement an electronic health record with patient access by 2006 *www.sutterhealth.org/about/news/news_emr.html*

D. Organizations Involved in Health Information Technology

ASSOCIATIONS AND MEMBERSHIP ORGANIZATIONS

AcademyHealth
www.academyhealth.org Professional society of public policymakers, business decisionmakers, health services researchers, policy analysts, economists, sociologists, political scientists, consultants, clinicians, and students. It is the national program office for two health policy initiatives funded through the Robert Wood Johnson Foundation: State Coverage Initiatives and Changes in Health Care Financing and Organization. AcademyHealth also is a contractor for both the Agency for Healthcare Research and Quality's User Liaison Program and the National Library of Medicine's Health Services Research Projects in Progress program.

American Academy of Family Physicians (AAFP)
www.aafp.org/index.xml A national association of family doctors, with more than 94,000 members in 50 states, the District of Columbia, Puerto Rico, the Virgin Islands, and Guam.

American Academy of Family Physicians Center for Health Information Technology (CHIT)
www.centerforhit.org Developed to promote and facilitate the adoption and optimal use of health information technology by AAFP members and other office-based clinicians. The focus of AAFP's technical expertise, advocacy, research, and member services associated with medical office automation and computerization.

American College of Physicians (ACP) Practice Management Center (PMC)
www.acponline.org/pmc Provides free assistance to ACP members covering business issues associated with running and working in a medical practice.

American Health Information Management Association (AHIMA)
www.ahima.org A national association for health information management professionals. AHIMA works to improve the quality of medical records and provides leadership in advocacy, education, certification, and lifelong learning.

American Hospital Association (AHA)
www.aha.org/aha/index.jsp A founding member of the National Alliance for Health Information Technology.

AHA's quality and patient safety page, with tools and resources
www.aha.org/aha/key_issues/patient_safety

AHA's HospitalConnect.com features the 2004 Most Wired Survey
www.hhnmag.com/hhnmag/jsp/articledisplay.jsp?dcrpath=AHA/PubsNewsArticle/data/0407HHN_FEA_Most_Wired&domain=HHNMAG

An article listing the 2004 Most Wired
www.usnews.com/usnews/health/mostwired/mw_wired.htm

An article on the 2005 Most Wired survey
news.zdnet.com/2110-9589_22-5519615.html

American Medical Informatics Association (AMIA)
www.amia.org A nonprofit 501(c)(3) membership organization of individuals, institutions, and corporations with the goal of developing and using information technologies to improve healthcare. AMIA is the official United States representative organization to the International Medical Informatics Association. Primary activities include the AMIA Annual Symposium, the AMIA Spring Congress, publication of the Journal of the American Medical Informatics Association, Working Groups, public policy initiatives, and the AMIA Resource Center.

Got EHR?
www.got-ehr.org An AMIA national initiative to promote the use of electronic health records for patient safety.

AMIA Primary Care Informatics Working Group
pciwg.amia.org Has the goal of making informatics technology serve the needs of patients and clinicians.

Association of American Medical Colleges (AAMC)
www.aamc.org A nonprofit association of medical schools, teaching hospitals, and academic societies that assists academic medicine's institutions, organizations, and individuals in medical education, medical research, and patient care.
Also see *www.aamc.org/newsroom/reporter/start.htm* for the AAMC Reporter, AAMC's flagship news publication.

College of Healthcare Information Management Executives (CHIME)
www.cio-chime.org/index.asp Mission is to serve the professional needs of healthcare chief information officers and to advance the application of information technology in innovative ways to improve the effectiveness of healthcare delivery.

Healthcare Information and Management Systems Society (HIMSS)
www.himss.org The healthcare industry's membership organization is focused on providing leadership for the optimal use of health care information technology and management systems to improve human health.

HIMSS Electronic Health Record home
www.himss.org/content/mindmaps/EHR/index.htm

HIMSS news ands research page
www.himss.org/ASP/indIntelHome.asp

HIMMS conferences and events page
www.himss.org/ASP/eventsHome.asp

HIMSS analytics page
www.himssanalytics.com/ASP/index.asp

HIMSS books and CDs
www.himss.org/ASP/storeHome.asp

2005 HIMSS Leadership Survey
www.himss.org/2005survey/healthcareCIO_home.asp

Institute for Healthcare Improvement (IHI)
www.ihi.org A not-for-profit organization leading the improvement of healthcare throughout the world.

Integrating the Healthcare Enterprise (IHE)
www.himss.org/ASP/topics_ihe.asp A multiyear initiative, for which HIMSS has taken a leadership role, that creates the framework for passing health information across the entire healthcare enterprise. Includes medical specialists and other care providers, administrators, standards organizations, information technology professionals, and vendors. IHE drives the adoption of standards to address specific clinical needs.

Medical Group Management Association (MGMA)
www.mgma.com Association of medical group practices works to improve their effectiveness and the knowledge and skills of those who manage and lead them.

Steering Committee on Clinical Information Technology (SCOCIT)
www.scocit.org A committee of the American Academy of Pediatrics (AAP) (formerly the Section on Computers and Other Technologies and the Task Force on Medical Informatics).

COALITIONS, COLLABORATIONS, AND PARTNERSHIPS

Bridges to Excellence
bridgestoexcellence.org/bte/bte_overview.htm Created by a group of employers, physicians, health plans, and patients to develop programs for realigning incentives around higher quality.

Certification Commission for Healthcare Information Technology (CCHIT)
www.os.dhhs.gov/healthit/cert_commission.html Created by HIMSS, AHIMA and NAHIT. Is developing a process for certifying EHR products for physician offices and also will consider product interoperability on a local and national scale, the use of incentives, and options for increasing the adoption of interoperable health information technology in the United States. A basic certification process is expected by the summer of 2005.

Connecting for Health
www.connectingforhealth.org Connecting for Health was established by the Markle Foundation and receives additional funding and support from the Robert Wood Johnson Foundation. It is a public-private collaborative designed to address the barriers to development of an interconnected health information infrastructure.

Connecting for Health reports:

Linking Health Care Information: Proposed Methods for Improving Care and Protecting Privacy, February 2005
www.connectingforhealth.org/assets/reports/linking_report_2_2005.pdf

Achieving Electronic Connectivity in Healthcare: A Preliminary Roadmap from the Nation's Public and Private-Sector Healthcare Leaders, July 2004
www.connectingforhealth.org/resources/cfh_aech_roadmap_072004.pdf

Connecting Americans to Their Healthcare, July 2004
www.connectingforhealth.org/resources/wg_eis_final_report_0704.pdf

EHR Collaborative
www.ehrcollaborative.org A group of organizations representing key stakeholders in healthcare. The collaborative has held meetings, audio sessions, and conference calls to gather input for the creation of a universal, standard electronic health record and passes this input along to Health Level 7, which conducts voting on the proposed standard.

Integrated Healthcare Association (IHA)
iha.org/p4pitms.htm A California group of health plans, physician groups, and health systems and large academic, purchaser, pharmaceutical industry, and consumer representatives involved in policy development and special projects involving integrated healthcare and managed care.

Joint Commission on Accreditation of Healthcare Organizations (JCAHO)
www.jhaco.org An independent, not-for-profit healthcare organization that evaluates and accredits more than 15,000 healthcare organizations and programs in the United States.

Joint Healthcare Information Technology Alliance (JHITA)
www.jhita.org An alliance between the American Health Information Management Association, the American Medical Informatics Association, the Center for Health Information Management, and the Healthcare Information and Management Systems Society. Advocates for legislation and regulation promoting the effective use of technology and its management.

The Leapfrog Group
www.leapfroggroup.org/FactSheets.htm An initiative driven by organizations that buy healthcare and that are working to initiate breakthrough improvements in the safety, quality, and affordability of healthcare.

National Alliance for Health Information Technology (NAHIT)
www.nahit.org A partnership of leaders from all healthcare sectors that is working to advance the adoption and implementation of healthcare information technology to achieve measurable improvements in patient safety, quality, and efficiency. The alliance brings together high-level executives from a wide range of healthcare organizations to agree on standards and share ideas for implementing technology. Its members include the American Hospital Association, the American Medical Association, the American Health Information Management Association, Blue Cross and Blue Shield Association, and Siemens Medical Solutions USA.

NAHIT made an influential recommendation on bar-coding drugs to FDA and helped create the Electronic Record Collaborative at *www.ehrcollaborative.org*.

National Alliance for Primary Care Informatics (NAPCI)
www.napci.org A coordinating group of primary care organizations committed to the development and implementation of a national strategy for the use of information technology and management in primary care.

Physicians' Electronic Health Record Coalition (PEHRC)
www.centerforhit.org/x199.xml Includes 14 medical organizations, representing more than 500,000 U.S. physicians. It helps physicians, especially those in small- and medium-size ambulatory care practices, to acquire and use affordable, standards-based electronic health records and other health information technology.

Public Health Data Standards Consortium
www.phdatastandards.info A voluntary confederation of federal, state, and local health agencies; national and local professional associations; public- and private-sector organizations; and individuals. This not-for-profit organization focuses on developing, promoting, and implementing data standards for population health practice and research.

FOUNDATIONS

California HealthCare Foundation (CHCF)
www.chcf.org An independent philanthropy formed to improve the way healthcare is delivered and financed in California and to help consumers make informed healthcare and coverage decisions. Conducts research and commissions surveys and reports on emerging technology trends and related policy and regulatory issues.

CHCF reports and initiatives
www.chcf.org/topics/index.cfm?topic=CL108

The eHealth Initiative and the Foundation for eHealth Initiative
www.healthinitiative.org Independent, nonprofit affiliated organizations whose missions are to drive improvement in the quality, safety, and efficiency of healthcare through information and information technology.

The Foundation for eHealth Initiative, in cooperation with the Health Resources and Services Administration Office for the Advancement of Telehealth, is implementing a $3.86 million grant program, ***Connecting Communities for Better Health***, to provide seed funding and support to multistakeholder collaboratives within both geographic and nongeographic communities that are using health information exchange and other information technology tools to drive improvements in healthcare quality, safety, and efficiency.
ccbh.ehealthinitiative.org/about/default.mspx

Connecting Communities for Better Health resource center
ccbh.ehealthinitiative.org

The eHealth State Health IT Policy Summit Initiative
www.ehealthinitiative.org/news/Louisiana.mspx

Information related to the meeting "Accelerating the Creation of State, Regional and Community-Based Health Information Exchange Organizations and Networks," December 2004
www.ehealthinitiative.org/december_6_meeting.mspx

The eHealth Initiative Global Health HIT Resource Center
ehealthinitiativelight.org/resourcecenter Provides an inventory of health information technology-related efforts for countries throughout the world.

Markle Foundation
www.markle.org The John and Mary R. Markle Foundation, Inc., has pursued a number of projects in the area of healthcare with the goal of addressing critical public needs through the innovative use of information and information technology.

RESEARCH AND EDUCATION ORGANIZATIONS

Center for Information Technology Leadership (CITL)
www.citl.org A research organization established to help guide the healthcare community in making more informed strategic information technology investment decisions. Chartered in 2002 by Boston-based, nonprofit Partners HealthCare System.

Center for Studying Health System Change (HSC)
www.hschange.com A nonpartisan policy research organization that designs and conducts studies focused on the U.S. healthcare system to inform the thinking and decisions of policymakers in government and private industry.

iHealthTech
www.healthtech.org A nonprofit research and education organization that develops objective technology forecasts and innovative decisionmaking tools and facilitates a learning network of experts and health system leaders for its partner organizations, which include healthcare systems, hospitals, safety-net providers, and government agencies.

The National Academies
www.nas.edu Brings together committees of experts in all areas of scientific and technological endeavor, including healthcare, to address critical national issues and give advice to the federal government and the public.

Institute of Medicine (IOM)
www.iom.edu A component of the National Academy of Sciences that serves as adviser to the nation to improve health. Provides science-based advice on matters of biomedical science, medicine, and health.

IOM Board on Health Care Services
www.iom.edu/board.asp?id=3809 Focuses on issues of healthcare organization, financing, effectiveness, workforce, and delivery, with special emphasis on quality, costs, and accessibility of care.

IOM Committee on Patient Safety Data Standards
www.iom.edu/psds Group within the Institute of Medicine that produces a detailed plan to facilitate the development of data standards that apply to the collection, coding, and classification of patient safety information.

Projects:

Crossing the Quality Chasm: The IOM Health Care Quality Initiative *www.nap.edu/books/0309072808/html/*

Data Standards for Patient Safety project
www.iom.edu/project.asp?id=4629

NAS Publications Related to Health and Information Technology:
For the Record: Protecting Electronic Health Information, 1997. Computer Science and Telecommunications Board
www.nap.edu/openbook/0309056977/html/R1.html#pagetop

The Computer-Based Patient Record: An Essential Technology for Health Care, 1997
books.nap.edu/catalog/5306.html

To Err Is Human: Building A Safer Health System, 1999
www.nap.edu/books/0309068371/html

Crossing the Quality Chasm: A New Health System for the 21st Century, 2001
books.nap.edu/openbook/0309072808/html/index.html

Key Capabilities of an Electronic Health Record System: Letter Report, 2003
books.nap.edu/openbook/NI000427/html/index.html

Patient Safety: Achieving a New Standard for Care, 2004
books.nap.edu/openbook/0309090776/html/index.html

List of IOM reports since 1998
www.iom.edu/reports.asp?view=topic%20

Medical Records Institute
www.medrecinst.com Promotes the goal of moving toward electronic health records, e-health, mobile health, and related applications of information technologies.

Practice Partner Research Network (PPRNet)
www.musc.edu/PPRNet/index.htm A practice-based research network linking physicians who use electronic medical records.

Public Health Informatics Institute
iha.org/p4pitms.htm The institute grew out of All Kids Count and evolved into the Public Health Informatics Institute in 2002. It helps health organizations apply and manage information systems.

E. Resources for Choosing an Electronic Medical Record

A directory of electronic medical record systems
www.telemedical.com/Telemedical/Products/emr.html

Advance for Health Information Executives Annual EHR Systems Review
health-care-it.advanceweb.com/common/editorial/PrintFriendly.aspx?CC=788

The 2004 review
health-care-it.advanceweb.com/resources/hx050104_p38_v2.pdf

American Academy of Family Physicians
www.centerforhit.org/x17.xml Resources for selecting and implementing an electronic health record.

American Academy of Family Physicians Center for Health Information Technology
www.centerforhit.org/x251.xml Electronic health record product reviews written by Academy members who are currently using EHRs.

Resources for selecting and implementing an electronic medical record system
www.centerforhit.org/x17.xml Includes a readiness assessment and sections on preparing the office, selecting a system, implementing a system, and maintaining and upgrading information technology.

American Academy of Pediatrics EMR review site
www.scocit.org/emr/index.php

DOQ-IT Vendor Evaluation Matrix
www.lumetra.com/doq-it/docs/Vendor%20Evaluation%20Matrix_020405.pdf

DOQ-IT electronic health record selection tools and resources
www.lumetra.com/doq-it/docs/EHR%20Selection%20Tools%20and%20Resources_020405.pdf

ElectronicHealthcare
www.electronichealthcare.net Provides reports of the performance of healthcare's information technology vendors.

Electronic medical record directory and resources from EMRConsultant.com
emrconsultant.com/theemrlist.php

Health IT Yellow Pages by Online Consultant Software EMR directory
olcsoft.com/yphcemr.asp

HIMSS guidance on system selection
www.himss.org/content/mindmaps/EHR/multi-maps/selection/selection.htm

Medical Economics electronic medical records page
www.memag.com/memag/article/articleList.jsp?categoryId=7152

Primer on Electronic Medical Records on EMRUPDATE.com
www.elmr-electronic-medical-records-emr.com/electronic_medical_record_Primer.htm An electronic records information site, includes an electronic medical record primer, a cost calculator, reference links, electronic medical record vendor comparisons, and more by Kirk Voekler, M.D.

"Your Guide to Electronic Health Records, Community Care Records, and Personal Health Records"
www.telemedicalrecord.com Features patient interactive personal health systems and clinician interactive electronic medical record systems.

F. Journals, News and Information Sources, and Trade Publications

JOURNALS

American Board of Quality Assurance and Utilization Review Physicians (ABQAURP) Journal
www.abqaurp.org/journal.asp ABQAURP provides healthcare education and certification for physicians, nurses, and other healthcare professionals.

Health Affairs
www.healthaffairs.org Peer-reviewed journal of health policy thought and research, published since 1981.

Health Affairs exclusives page, with online-only journal articles
www.healthaffairs.org/WebExclusivesredirect.php/Pauly_Web_Excl_082802.htm

Informatics in Primary Care
www.radcliffe-oxford.com/journals/J12_Informatics_in_Primary_Care
Provides information and guidance on information technology and information management in primary care.

Journal of the American Medical Informatics Association (JAMIA)
www.amia.org/index.html The American Medical Informatics Association's bimonthly journal, providing peer-reviewed articles for physicians, informaticians, scientists, nurses, and other healthcare professionals.

Journal of Healthcare Information Management (JHIM)
www.himss.org/asp/publications_jhim.asp Peer-reviewed journal for healthcare information and management systems professionals.

Journal of Medical Internet Research (JMIR)
www.jmir.org International scientific peer-reviewed, open access journal on all aspects of research, information, and communication in the healthcare field using Internet- and Intranet-related technologies.

Journal of Open Source Medical Computing (JOSMC)
www.josmc.org An electronic forum for disseminating information on free and open source medical computing. Peer-reviewed articles, feature and trend articles and resources such as links, datasets, software, and other materials that developers want to make available to the free and open source community. JOSMC posts informational notices and summaries of conferences and other events of interest to the free and open source community.

MD Net Guide
www.mdnetguide.com A peer-reviewed series of medical journals for physicians covering the intersection of healthcare and technology.

NEWS AND INFORMATION

Advance for Health Information Professionals
health-information.advanceweb.com A bi-weekly publication that provides information in the field of health information management. The publication has strong editorial relationships with the American Health Information Management Association and the American Association for Medical Transcription.

American College of Physicians Observer (ACP)
www.acponline.org/journals/news/obstoc.htm?hp Provides news and information for internists about the practice of medicine and reports on the policies, products, and activities of ACP.

American Medical News
www.ama-assn.org/amednews The American Medical News Web site, amednews.com, provides full text of all articles, free e-mail alerts listing new content, and a full-text medical news channel for handhelds and wireless. Published by the American Medical Association.

ElectronicHealthcare
www.electronichealthcare.net Provides reports of the performance of healthcare's information technology vendors.

FasterCures SmartBrief
www.smartbrief.com/fastercures/?campaign=fastercures%20Headlines

HealthcareITNews
www.healthcareitnews.com Published in partnership with HIMSS.

iHealthbeat.org
www.ihealthbeat.org An online publication by the California Healthcare Foundation that provides news on health information technology and its impact on healthcare.

Informatics-Review
www.informatics-review.com An electronic serial that provides information to medical and information system professionals on academic developments in clinical informatics and computing.

LinuxMedNews
www.linuxmednews.com Provides Linux and open source software medical software news as well as articles and a comprehensive listing of open source and Linux medical software projects.

21st Century Health Care Caucus Electronic Newsletter
www.himss.org/HTMLEmail/21stcenturycaucus/21stcentury_200502.html
Provides information on U.S. government developments in health information technology.

TRADE PUBLICATIONS AND TRADE NEWS

AHANews.com
www.ahanews.com/ahanews/index.jsp Daily report for healthcare executives by the American Hospital Association.

AIS E-Health.com
www.aishealth.com/EHealthBusiness/021705.html A channel on AISHealth.com providing news, data, and strategic information on the business of healthcare.

Healthcare Informatics
www.healthcare-informatics.com A monthly business magazine that provides information about information technology for information technology executives and managers in healthcare facilities and other organizations.

Health Care's Most Wired Magazine
www.hhnmostwired.com/hhnmostwired/index.jsp An American Hospital Association online publication, features articles for hospital and health systems executives in the area of technology leadership and information technology.

Health Data Management
www.healthdatamanagement.com A trade magazine focusing on data management in healthcare and other areas of health information technology.

HealthIT World
www.health-itworld.com Provides information on business, technology, and product developments related to healthcare management systems. Includes information relation to health information and clinical trials and patient diagnostics, treatment, and care for executives and managers.

Managed Healthcare Executive
managedhealthcareexecutive.com Provides analysis on the business of healthcare to managed care executives, medical directors, pharmacy directors, and other healthcare professionals.

NetworkWorldFusion
www.nwfusion.com Publishes network information technology news. Has an online research center and features network IT and business executives news. Also provides information and news on security and HIPAA.

G. Information on State Initiatives

Arkansas
ihealthbeat.org/index.cfm?Action=dspItem&itemID=107838

Kentucky
www.ama-assn.org/amednews/2005/04/04/bisc0404.htm

Maine
www.dirigohealth.maine.gov/dhsp07f.html

Massachusetts
www.maehc.org

Michigan
www.memri.us/faq.html

Nebraska
www.ihealthbeat.org/index.cfm?Action=dspItem&itemID=109749

New Jersey
philadelphia.bizjournals.com/philadelphia/stories/2005/05/09/daily24.html

Oregon
www.superiorconsultant.com/Pressroom/superiorHealth/DailyNews/May%5C051205_SHArchive.asp

Pennsylvania
www.pharma-lexicon.com/medicalnews.php?newsid=21277&language=spanish

Wisconsin
www.madison.com/archives/read.php?ref=tct:2005:02:04:402701:FRONT

H. Personal Health Record Organizations and Initiatives

CapMed
www.capmed.com Has developed personal health record products, such as the Personal Health Record and the Personal Health Key.

Health Record Network (HRN)
www.healthrecord.org Seeks to create broad-based consumer demand for information technology-based products such as personal electronic health records.
www.healthrecord.org/pdfs/HRNConceptOverview.pdf for the concept overview.

MedCommons Patient Data Bank
secure.medcommons.net/hp.html Provides a national patient-centric personal health information storage and retrieval system. The software used is provider, vendor, and policy neutral.

I. Open Source Groups and Initiatives

American Academy of Family Physicians Center for Health Information Technology
www.centerforhit.org/x337.xml AAFP CHIT's open source medical projects page, providing a list of open source medical projects.

The Bioinformatics Organization, Inc.
Bioinformatics.org One of the largest affiliations in the field of bioinformatics, offering a variety of resources and open membership and project hosting. It is known for its emphasis on open access to biological information and free and open source software.

LinuxMedNews project page
www.linuxmednews.com/linuxmednews/LMNProjects/Projects/folder_contents Medical news project page that includes reviews and resources on open source projects.

openEHR
www.openehr.org An international not-for-profit foundation working toward the goal of having interoperable, life-long electronic health records.

OpenGALEN
www.opengalen.org/index.htmlOpenGALEN A not-for-profit organization dedicated to bringing GALEN to the world as an open source resource.

Open Source Health Care Alliance
www.oshca.org A collaborative forum for promoting and facilitating open source software in human and veterinary healthcare. OSHCA promotes the open source software concept in healthcare and helps policymakers, commercial enterprises, and users take advantage of the benefits of open source.

Open Source Health Informatics Working Group (OSWG) of the International Medical Informatics Association (www.imia.org)
www.chirad.info/imiaoswg Brings together experts and others from a wide range of health professions who are interested in the potential application of free and open source solutions.

Open Source Initiative (OSI)
www.opensource.org A nonprofit corporation dedicated to managing and promoting the Open Source Definition, specifically through the OSI Certified Open Source Software certification mark and program.

Sourceforge.net
sourceforge.net/softwaremap/trove_list.php?form_cat=266
Provides a directory of open source healthcare software projects and a centralized location for open source software development.

The Spirit Project
www.euspirit.org A multilingual source for best practice open source news and software for healthcare.

Universidade Federal de Sao Paulo's directory of open-source healthcare software projects
www.unifesp.br/dis/set/links/root_opensourcehealthcare.html

VistA Resources

American Academy of Family Physicians' Center for Health Information Technology's VistA page
www.centerforhit.org/x346.xml

An online community to promote VistA and to help developers and users implement the software
www.hardhats.org

OpenVistA page
www.worldvista.org/openvista

VistA history
www.worldvista.org/vista/history

WorldVistA, a nonprofit, 501(c)(3) public-benefit corporation created to improve health worldwide by making medical software better and more accessible *www.worldvista.org*

J. Security and Privacy

American Hospital Association HIPAA home page
www.hospitalconnect.com/aha/key_issues/hipaa Includes privacy and security resources.

Centers for Medicare and Medicaid HIPAA page
www.cms.hhs.gov/hipaa/hipaa1/default.asp?

The Department of Health and Human Services Office for Civil Rights HIPAA page
www.hhs.gov/ocr/hipaa

HIPAA training and consulting services site with FAQs and information on HIPAA compliance
www.hipaaclickandcomply.com/y-hipaa/terms-j.html

Indepth information on biometrics
www.bromba.com/faq/biofaqe.htm

Privacy Rights Clearinghouse
www.privacyrights.org A nonprofit consumer information and advocacy organization. Web site includes resources, fact sheets, and text of speeches.

www.privacyrights.org/medical.htm for medical privacy resources

www.privacyrights.org/medical.htm#FactSheets for fact sheets on medical privacy

www.privacyrights.org/medical.htm#Speeches for speeches and articles on medical privacy

K. Information on Databases and SQL

Database Models
unixspace.com/context/databases.html Information on different database models, including hierarchical model, network model, relational model, object/relational model, object-oriented model, semi-structured model, associative model, and more.

Data Warehousing Information Center
www.dwinfocenter.org Features a collection of one practitioner's essays on data warehousing.

db.grussell.org Database basics site focusing on online database learning and including information on SQL and database analysis.

Digital Web Magazine's Introduction to Databases
www.digital-web.com/articles/introduction_to_databases

Dilip's Brief Introduction to Relational Databases
www.cs.unc.edu/Courses/wwwp-s98/members/barman/databaseLesson

FAQ on SQL
epoch.cs.berkeley.edu:8000/sequoia/dba/montage/FAQ/SQL_TOC.html

A Gentle Introduction to SQLInteractive, SQL tutorial
www.sqlzoo.net

L. Clinical Research Databases and Related Sites

Academic Health Centers Clinical Research Forum
www.ahcforum.org An organization of 40 academic health centers working to address national problems surrounding clinical research, including deficiencies in the training, funding, and infrastructure for clinical investigators. The Forum brings together its members, national leaders, and others to facilitate discussion of critical issues in clinical research policy; serve a national advocacy role for clinical research; respond to initiatives on clinical research from other organizations; and share best practices, successes, and failures in clinical research. It also advocates for increased support for clinical research in general and to raise awareness of the essential role that academic health centers have in alleviating human suffering and improving quality of life.

American College of Cardiology-National Cardiovascular Data Registry® (ACC-NCDR®)
www.accncdr.com/WebNCDR/Default.aspx

ClinicalTrials.gov
clinicaltrials.gov Provides up-to-date information for locating federally and privately supported clinical trials for a wide range of diseases and conditions. Currently contains approximately 12,700 clinical studies sponsored by the National Institutes of Health, other federal agencies, and private industry.

Cochrane Collaboration
www.cochrane.org/index0.htm An international not-for-profit organization, providing information about the effects of healthcare. The Cochrane Library contains regularly updated evidence-based healthcare databases.

DoCDat
www.lshtm.ac.uk/docdat/page.php?t=index A directory of clinical databases in the United Kingdom that provides a brief description of each database, including what it covers and how it is managed. It provides a simple review of the quality of the data and contact details of the custodian of each database.

Health Legacy Partnership
www.healthlegacy.org Founded by the Joseph H. Kanter Family Foundation and the Agency for Healthcare Research and Quality, aims to create a public/private effort to improve healthcare decisionmaking. Supports the development of a national outcomes database to be used by doctors and patients to determine which treatments work best for specific diseases and conditions.

Office of Rare Diseases (ORD)
rarediseases.info.nih.gov
Research and clinical trials page:
ord.aspensys.com/asp/resources/rsch_trials.asp. Provides online resources and databases on completed, current, and planned rare disease studies.

PDQ – NCI's Comprehensive Cancer Database
www.cancer.gov/cancer_information/doc.aspx?viewid=9D617786-179B-4DB7-8664-885DD33E7D51

Society of Thoracic Surgeons National Database
www.sts.org/sections/stsnationaldatabase

M. Online Forums, Listservs, and Discussion Boards

American Academy of Family Physicians Center for Health Information Technology electronic medical records e-mail discussion list
www.centerforhit.org/x687.xml

Docsboard.com
www.docsboard.com/forums/forumdisplay.php?f=4
Discussion lists for doctors, includes electronic medical records discussion

Dr. Kirk G. Voelker electronic medical record discussion forums
www.emrupdate.com/Forum

Foundation for eHealth Initiative's Connecting Communities for Better Health Discussion Forum
ccbh.ehealthinitiative.org/forum/Default.aspx?Group=6 Brings health information organizations together to discuss clinical, financial, legal, organizational, and technical challenges.

Indian Health Service Electronic Health Record Listserv
www.ihs.gov/CIO/EHR/index.cfm?module=listserv

Medical Records Institute mailing list
www.medrecinst.com/iebms/reg/reg_p1_form.aspx?oc=10&ct=MAILLIST&eventid=5015

Medical Records Institute online forums for discussion of various EMR topics
www.medrecinst.com/forum/default.asp

National Institutes of Health health information technology listserv
list.nih.gov/archives/health-it.html

Steering Committee on Clinical Information Technology (SCOCIT) of the American Academy of Pediatrics listserv
www.aapscot.org/listserv.php

N. Health Information Technical Glossaries

AISHealth.com "E-Health Terms in Plain English"
www.aishealth.com/EHealthBusiness/EHealthTerms.html

Corporation for Research and Educational Networking (CREN)
www.cren.net/crenca/glossary/crenglossary.html

DOQ-IT glossary
www.doqit.org/doqit/jsp/index.jsp?main=../includes/glossary.html#EHR

An EHR "Hardware and Software Glossary of Terms" by Lumetra
www.lumetra.com/doq-it/docs/EHRGlossary_011805_v4_1.pdf

O. Other Useful Resources

The 21CFRPart11.com Web site
www.21cfrpart11.com/index.html Provides access to information on the rule and also maintains an e-mail list for discussion. It also includes the latest conference, meeting, and seminar information and links to vendors and consultants that can provide help with issues of compliance with regulations and productivity for the pharmaceutical community.

American Medical Informatics Association (AMIA)
www.amia.org/history Information on the history of medical informatics.

Healthcare Informatics Online
www.healthcare-informatics.com/issues/2003/05_03/cover_ehr.htm
Article with commentary on the use of terms in discussing electronic medical records.

Overview of the bills that were under consideration in the 108th Congress concerning health information technology
www.hhs.gov/healthit/documents/LegistnonHIT.pdf

For up-to-date information on legislation, see *thomas.loc.gov/home/search.html* for the bills and resolution search page, where searches can be conducted by key word(s) or bill number.

Appendix G

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7. Baker, M.L., National health info network needs safeguards. eWeek, February 7, 2005. *www.eweek.com/article2/0,1759,1761542,00.asp*
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